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Coping Responses to Positive Genetic Suceptibility Test Results for Alzheimer's Disease

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Abstract

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Test Results for Alzheimer's disease

By

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MS, Mercy College, 2006

BS, Iona College, 1996

Dissertation Submitted in Partial Fulfillment

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Abstract

Genetic susceptibility test results have been found to cause differences in coping behavior following testing for the APOE-ε4 gene, associated with Alzheimer's disease. Coping behaviors differ within the first 12 months of testing. Currently, no studies have been conducted beyond the first 12 months comparing positive (P) and negative (N) groups or how sex relates to coping behavior based on positive test results. Based on the theory of primary and secondary control, and theory of stress, appraisal, and coping. This study compared differences in coping strategies based on genetic test results and between sexes with positive test results beyond the first 12 months. Participants (280) who had undergone testing for the APOE-ε4 gene 12 or more months prior to the study and had a relative diagnosed with AD were selected. Coping strategies were measured using the Brief COPE scale. Using independent measures *t* tests, the data were analyzed, and test results were significant, indicating there are differences in coping between P and N groups. The P group reported significantly higher levels of cognitive and emotional coping strategies than the N group 12 or more months after receiving test results. These findings were consistent with previous studies that produced significances in cognitive and emotional coping strategies between groups, in the first 12 months. The findings were non significant for cognitive and emotional coping strategies for sex in the positive group. This study contributes to social change by adding information and knowledge that can impact decision making by individuals with positive test results for the APOE-ε4 gene in making financial changes, life styles changes, and family and work adjustments affecting their community and society.

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Dedication

This dissertation is dedicated to my family: my daughters Sharon and Lauren, my granddaughter Sharina, my great-grandson Detrel, and our cat Stevie who sat with me late at night when everyone else was asleep.

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I give special thanks to God the Father and my Lord and Savior Jesus Christ for giving me the strength to make this journey. To my family without whose encouragement and understanding I would not have been able to complete this journey. I thank my committee members Dr. Maureen Levine and Dr. Sandra Mahoney for their patience with me during these many months. I thank Dr. Albert Manzi my statistician and mentor. I also thank Dr. Dorthy Balancia and Dr. Eleanor Panovi for their encouragement.

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Chapter 1: Introduction to the Study

Introduction

Alzheimer's disease (AD) is a form of dementia for which presently there is no cure; AD causes neurodegeneration of brain tissue that ultimately leads to death (Mohandas, Rajmohan, & Raghunath, 2009). AD is estimated to affect 5.3 million people of all ages in the United States, and 5.1 million are 65 years old or over (Alzheimer's Association, 2011). According to the Alzheimer's Association (2011), the number of people with AD will increase to twice this number by 2050. There are four types of AD, but late onset familial AD (LOFAD) and late onset AD (LOAD) are the most common forms of AD, with onset occurring after age 65 (Green, 2007; Shepherd, Grace, Mann, & Halliday, 2007). Early onset familial AAD (EOFAD) and early onset AD (EOAD) occur before age 65 (National Institute on Aging [NIA], 2010). This chapter includes the background of the study, problem statement, nature of the study, the research questions and hypotheses, purpose of the study, the theoretical bases for the study, definition of terms used, assumptions and limitations of the study, significance of the study, and summary of the chapter.

Currently, through genetic testing, susceptibility for developing AD in the future can be detected (Green, 2007). Individuals receiving positive susceptibility test results for developing AD in the future may view the information as a perceived threat (Hock & Krohne, 2004). Individuals receiving negative susceptibility test results and who have a family history of AD may also perceive the information as a lower risk factor (Roberts, Christensen, & Green, 2011). According to Roberts et al. (2011) the absence of the

APOE-4 negative gene may lower the risk of developing AD; however, general health and family history must be considered. Fanshawe et al. (2008) reported 24% of participants who received negative susceptibility test results for AD changed health behavior coping strategies. Most recently, it has been found that chronic health conditions such as high cholesterol, Type II diabetes mellitus, and hypertension are contributing factors in the development of AD (Kirbach & Mintzer, 2008; Reitz et al., 2010; Roberts et al., 2011). The perceived threat of developing AD may develop into a condition of chronic stress, which could lead to depression (Monroe, Salvich, Gotlib, & Torres, 2007).

Coping strategies change under chronic stress situations and based on sex, with individuals changing from using cognitive strategies to using emotional strategies (Chipperfield, Perry, Balis, Ruthig, & Loring, 2007). Individuals may change their coping strategies as a way to avoid or limit the risk of developing AD (Roberts et al., 2011). According to Ingledew and McDonagh (2000), health behavior changes are often used as coping strategies as part of preventive measures. Chao et al. (2008) found individuals with positive or negative susceptibility test results changed their health behavior coping strategies based more on their family AD history than on genetic susceptibility testing results. Chipperfield et al. (2007) examined coping strategies used by the sexes when under chronic health-related stress. The researchers found women tend to use secondary coping strategies, which have been classified as emotional coping strategies by Skinner (2007), more often than men.

Current literature suggests that more research needs to be conducted on the impact of positive and negative susceptibility for AD on types of coping strategies used and

based on sexes (Gooding, Organista, Burack, & Biesecker, 2006; Linnenbringer, Roberts, Hiraki, Cupples, & Green, 2010; Vernarelli et al., 2010). As genetic susceptibility testing becomes more readily available to the general public (Roberts et al., 2011; Zonno & Terry, 2009), changes in coping behaviors and the reasons for those changes become important issues for psychologists and mental health professionals. Coping behavior changes may be viewed as the result of fear of developing AD and maybe an attempt by individuals to prevent or reduce the risk of developing AD (Roberts et al., 2011: Zonno & Terry, 2009). Individuals' families may be affected by these changes in behavior such as individuals purchasing additional health, life, disability and long-term care insurances at greater premiums (Zick et al., 2005). These families may also experience the fear of their loved ones developing AD. The focus of this study was to compare differences in coping strategies between a group who had positive (P group) and a group who had negative (N group) genetic susceptibility test results. This study also considered how sex relates to coping strategies with positive genetic susceptibility for developing AD in the future.

Background of the Study

The public's increased awareness of AD; the negative impact of the risk factors for developing AD based on family history, gender, age, health, and genotype; and the availability of genetic susceptibility testing for AD have caused an increase in requests for genetic susceptibility testing for AD (Goldman et al., 2011). Research studies such as the Risk Evaluation and Education for Alzheimer's disease (REVEAL) have over the past 12 years collected data at several sites in the United States on behavioral changes in individuals who received positive and negative susceptibility test results for developing

AD based on genetic factors (Green, 2007). The REVEAL studies were a series of ongoing, government-funded studies on genetic susceptibility testing (Green, 2007). Currently there have been three studies conducted. Each study used participants who had a family member or members diagnosed with AD. Comparisons were made between data sets in some studies where the same research questions were studied (Green, 2007).

The first REVEAL studies sponsored by the National Human Genome Research Institute (NHGRI) examined the psychological impact (depression and anxiety) of the participants receiving positive test results (Green, 2007). The study enlisted 301 participants (Green, 2007). In the second study, REVEAL II studied the effect of receiving genetic test results through an educational and counseling protocol (Green, 2007). Comparisons were made between the data from each of the REVEAL studies (Green, 2007). The study was sponsored by the National Institute on Aging (NIA) and enlisted 360 participants (Green, 2007).

The third study, REVEAL III, focused on risk perception and health changes; the study was sponsored by NHGRI and enlisted 280 participants (Green, 2007). The researchers conducting all three studies were specialists in genetics and genetic testing (Green, 2007). The participants used in the three REVEAL studies were participants from 18 to 85 years old who were children or siblings of persons who had been diagnosed with AD (Green, 2007). The REVEAL studies enlisted a total of 941 participants; of that number, 79% were females (Green, 2007). The researchers conducting those studies were concerned that this large percentage of females would affect results obtained (Green, 2007).

The main focus of the REVEAL studies has been on the individuals' psychological responses following positive susceptibility test results (Fanshawe et al., 2008). Some of the research questions addressed by the REVEAL studies were related to individual risk perception, health behavior changes, and depressive and anxiety behavioral changes (Green, 2007). The REVEAL studies did not address sex differences in behavioral changes (Green, 2007). The participants in the REVEAL studies were placed in groups of either positive or negative genetic susceptibility test results, not in groups based on sex (Green, 2007). The relevant REVEAL studies will be discussed in Chapter 2.

None of the REVEAL studies compared coping differences between sexes or addressed coping strategies used by the participants after positive or negative susceptibility test results for AD. An extensive search of the literature did not produce any REVEAL studies that explored sex differences or the use of coping strategies.

This current study compared coping strategies based on genetic susceptibility test results and compared coping strategies between sexes with positive genetic susceptibility test results in the 12 month or more period following receiving their test results. Currently, the literature reports monitoring of individuals who receive positive susceptibility test results for AD for the first 12 months, focusing on psychological changes such as depression and anxiety (Ashida et al., 2010; Gooding et al., 2006; Vernarelli et al., 2010). The current study focused on individuals who had received positive or negative genetic susceptible test results and the coping strategies they employed 12 months or more after receiving susceptibility test results. Examining the

effect of positive and negative genetic susceptibility test results on cognitive and emotional coping strategies may create a better understanding of the individuals' behavior.

In Chapter 2, I present an extensive and detailed review of research on coping strategies and the effects of sex on coping strategies as well as a more detailed description of the studies presented in this introduction.

Problem Statement

To date, limited studies outside of the REVEAL studies have been conducted comparing genetic susceptibility test results or on how sex is related to coping strategies used when one is faced with a positive genetic susceptibility for developing AD in the future. All of the studies found were conducted within the first 12 month period following test results. No studies focused on individuals' coping strategies after the first 12-month period. A search of the literature produced only one study on stress and coping strategy following genetic susceptibility testing for AD, that of Gooding et al. (2006). Gooding et al. suggested it is important to understand the relationship between sex and cognitive and emotional coping strategies following a test result of positive genetic susceptibility for AD. This suggestion has also been expressed by Vernarelli et al. (2010) and Linnenbringer et al. (2010), who also suggested further study needs to be conducted on the effect of positive genetic susceptibility test results. Current studies have found that changes in coping behaviors in diet, dietary supplement use, and health behavior have occurred following positive and negative genetic susceptibility test results for AD within the first 12 months. There are no studies focusing on coping after the first 12 months.

This gap in the literature limits psychologists and mental health professionals from fully understanding individual differences and sex differences in coping strategies following positive genetic susceptibility test results for AD beyond the first 12 months. This gap also prevents psychologists and mental health professionals from better understanding the individuals' mental state and limits the formulation of effective and thoughtful treatment plans that are sex specific.

Purpose of the Study

The purpose of the quantitative survey was to examine the relationship of the independent variables, testing results (positive and negative) and sex (males and females), on the dependent variables, cognitive and emotional coping strategies used by participants following genetic susceptibility testing for the APOE-4 gene associated with developing AD. Coping strategy differences between groups of participants who had received positive or negative genetic susceptibility testing results for the APOE-4 gene were examined. The study also examined the differences between the independent variable sex for individuals who received positive susceptibility results for the APOE-4 gene on the dependent variables cognitive and emotional coping strategies. The study included participants who had received their test results 12 or more months prior to the study.

The information obtained from the study may help psychologists and mental health professionals become more aware of this special group of individuals. The information may aid psychologists and mental health professionals in developing effective treatment plans for this special group. As the availability of testing for

susceptibility for AD grows, so will the number of individuals within this special group. This study, as a way of effecting social change, encourages a more positive view of behavior beyond the 12 month period following genetic susceptibility test results for AD. This study, by decreasing fear of genetic testing results and the current negative view of genetic susceptibility test results for AD, will increase public awareness and present a more positive view of genetic susceptibility test results for AD and on behavior changes such as healthcare, health insurance, life insurance, future financial planning, family, and community relationships.

Research Questions and Hypotheses

The research questions and hypotheses that guided the study were:

1. Are there significant differences in coping strategies between the positive (P) group and the negative (N) group following genetic susceptibility test results for developing AD in the future, in the 12 months or more period after receiving the test results, as measured by the Brief COPE scale?

*H*o1: There are no significant differences in coping strategies as measured by the Brief COPE scale, between the P group and the N group following genetic susceptibility test results for developing AD in developing AD in the future, in the 12 months or more period after receiving the test results.

*H*a1: There are significant differences in coping strategies as measured by the Brief COPE scale, between the P group and the N group following genetic susceptibility test results for developing AD in the future, in the 12 months or more period after receiving the test results.

2. Are there significant differences in the use of coping strategies by sex, used by participants who received positive susceptibility test results for developing AD in the future, in the 12 months or more period after receiving the test results, as measured by the Brief COPE scale?

*H*o2: There are no significant differences in coping strategies by sex as measured by the Brief COPE scale used by the participants who received positive susceptibility test results for developing AD in the future, in the 12 months or more period after receiving test results.

*H*a2: There are significant differences in the use of coping strategies by sex, as measured by Brief COPE scale used by the participants who received positive susceptibility test results for developing AD in the future, in the 12 months or more period after receiving test results.

Nature of the Study

This quantitative between groups survey studied cognitive and emotional coping strategies used between a P group and an N group following genetic susceptibility test results. This between-groups survey examined differences in cognitive and emotional coping strategies used between sexes who had received positive genetic susceptibility test results for developing AD in the future.

In Chapter 3, I present a more detailed description of the design and of the methodological procedure used to answer the research questions and to assay the hypotheses of this study.

Theoretical Base

There are many theories of coping strategies/styles within the field of psychology (Skinner, Edge, Altman, & Sherwood, 2003). To understand the different coping strategies individuals might use when diagnosed with a positive or negative susceptibility for developing AD in the future, I selected two coping theories: Rothbaum, Weisz, and Snyder's (1982) theory of primary and secondary control and Lazarus and Folkman's (1984) theory of stress, appraisal, and coping. Rothman et al. (1982) theorized that coping consists of two factors: primary-control coping, which consists of changing the situation or emotion, and secondary-control coping, which consists of adapting to the problem situation or emotion, also known as acceptance (Skinner, 2007). Individuals' perception of control over the situation determines which coping strategy will be used (primary or secondary control; Skinner, 2007).

Lazarus and Folkman (1984) theorized that coping consists of two factors: problem-focused coping that focuses on the source of the stressor and emotional-focused coping that reduces negative emotions (Connor-Smith & Flachsbart, 2007). In problem-focused coping, individuals actively attempt to reduce or eliminate the stressful situation. In emotional-focused coping, individuals attempt to relieve the stressful situation by denying its presence. Females have been found to use emotional-focused coping strategies under stressful situations more often than males (Kim, Knight , & Flynn-Longmire, 2007).

Research has been conducted using these two theories to examine coping differences under chronic stress conditions between different ages, sexes, socioeconomic

status, and education (Chipperfield et al., 2007; Howerton & VanGrundy, 2009). The two theories are the ones reported in the literature to be most often used by individuals faced with stressful situations (Skinner, 2007). Each of these theories can be used to study the coping strategies of individuals who had received positive genetic susceptibility test results, in comparison to individuals who had received negative genetic susceptibility test results. These theories can also be used to examine the coping strategies used by the sexes who had received positive genetic susceptibility test results. Each of these theories is explored in depth in Chapter 2.

Definition of Terms

Alzheimer's disease (AD): A form of dementia that is a neurodegenerative, incurable disease with a slow progression. Signs of the disease are cognitive impairment, problems in judgment and decision-making, problems in language (e.g., apraxia, inability to perform a series of movement, and aphasia, inability to articulate in sentence or phrase form), loss of memory, loss of body functions, and aphasia that finally lead to death (Blennow, deLeon, & Zetterberg, 2006).

Chronic stress: A physical or psychological strain with slow onset and long duration (Marin, Martin, Blackwell, Stetler, & Miller, 2007).

Cognitive appraisal: The evaluation, identification, and classification of a stressful event by the individual (Cheng & Cheung, 2005).

Coping: Cognitive and behavioral attempts to master, change, reduce, minimize, or regulate internal or external stress (Skinner et al., 2003).

Dementia: The deterioration of cognitive and judgmental functions (Ballenger, 2006).

Early onset Alzheimer's disease (EOAD): A type of AD that is not genetically linked; it is sporadic, and it has an early onset before age 65 (Vernarelli et al., 2010).

Early onset familial Alzheimer's disease (EOFAD): A type of AD that is genetically linked to first- or second-degree relatives and that has an early onset before age 65 (Vernarelli et al., 2010).

Emotion-focused coping: The attempt to relieve the emotional stress of a stressful situation by denial (Kim et al., 2007).

Genetic testing: Genetic testing in this study referred to the examination of DNA to determine the presence of defective genes related AD.

Late onset Alzheimer's disease (LOAD): A type of ADthat can be either autosomal dominant (inherited factors by first degree relative) or sporadic (no inherited factors) and has an onset after age 65 (Bird, 2009).

Perceived control: The experiences and beliefs individuals have about their ability to control the outcome of events in their life; the individuals' ability to control or shape events (Skinner, 2007).

Perceived risk: For this study, perceived risk was individuals' level of belief in their susceptibility for developing AD (Hiraki, Chen, Roberts, Cupples, & Green, 2009).

Primary control: The attempt by individuals to change their environment, to influence the event, or alleviate the symptoms of the stressor to fit their needs (Skinner, 2007).

Problem-focused coping: The process of actively doing something to relieve or alleviate a stressful situation (Connor-Smith & Flachsbart, 2007).

Problem-solving social support: The act of gathering information to help plan and cope with a stressful situation (Riolli & Savicki, 2010).

Risk Evaluation and Education for Alzheimer Disease (REVEAL): An ongoing study whose focus is on the effect of genetic testing for AD on gender, ethnicity, ethics, psychological impact, education, and disclosure.

Secondary control: The attempt by individuals to fit into their environment, to accept the circumstance or events that they cannot control (Skinner, 2007).

Assumptions and Limitations

The current study assumed the participants' positive susceptibility test results for developing AD in the future would affect the participants' coping strategies. It was assumed the participants in the study would honestly and openly answer all questions. It was assumed the instrument used in the study, the Brief COPE Scale, was a reliable and valid tool for measuring coping skills. It was assumed the participants' responses to the scales' questions will be honest responses. It was assumed all participants have access to a computer with Internet services and that all participants were computer literate.

The limitations of the survey were that the special population to be used in the study limits the generalizability of the results to other chronic diseases. The selection of the participants was not random. The lack of information about the participants' coping behaviors prior to receiving positive or negative genetic test results limited the ability to compare coping strategies prior to genetic testing. Further limitations were that the poster

announcing the study and the survey were posted online and required potential participants to have access to a computer with Internet service and be competent in using a computer.

The delimitations of the study were that the participants were all adults between the ages of 45 and 75 years old and had undergone genetic susceptibility testing for AD. The participants received a positive or negative susceptibility test result for the APOE-4 gene associated with the development of AD. The Brief COPE scale assessment tool was be completed in one session.

Significance of the Study

As the number of those seeking genetic testing for susceptibility to diseases like AD grows, so does the need for competent psychological counseling before, and more importantly, after genetic test results. Currently, based on the literature, there have been only a limited number of studies done on coping strategies used by individuals with positive genetic test results for AD (Gooding et al., 2006). Health behaviors and perceived risk studies conducted have covered only the first 12 months. A search of the literature produced limited studies or research comparing coping strategies between individuals with positive susceptibility test results for AD with individuals with negative susceptibility test results. No studies or research was found beyond the first 12 month period following genetic susceptibility test results.

An extensive search of the literature did not produce any study addressing coping strategies for sexes with positive genetic susceptibility test results for AD. These gaps in the literature limit psychologists and mental health professionals from fully

understanding changes in coping behavior individuals might make and from better understanding the individuals' mental state. These gaps also limit the formulation of effective and thoughtful treatment plans that are sex specific. The family is also affected by these gaps. The family is limited from having a clearer understanding of the changes that a loved one may make based on positive genetic susceptibility test results for developing AD in the future. Changes in behavior such as increased healthcare provisions, life insurance, long-term care, finances, and health insurance affect the family unit's financial stability (Zick et al., 2005).

This study adds to the current body of literature on AD susceptibility to alert psychologists and mental health professionals of the need to develop effective treatment plans that are sex sensitive. AD affects 5.3 million people of the general population. The general public is becoming more and more accepting of genetic testing, but has little knowledge of what comes after the testing. The current study hoped to enlighten the general public about possible coping strategies individuals may employ if given positive susceptibility test results for AD. The study also helps to clarify coping behaviors that occur within this special population for psychologists, mental health professionals, family, and the general public. Public awareness of the impact of positive genetic susceptibility test results on individuals' coping behavior may help to bring families and communities together.

Summary

Researchers have found that individuals receiving positive susceptibility test results for developing AD in the future may develop a chronic stress condition. Perceived risk and uncertainty are cited as the main cause of the chronic stress. There have been limited studies conducted into the coping strategies individuals might use to regain and maintain control over their lives, and which coping strategies are preferred over others based on sex. Conducting comparisons of cognitive and emotional coping strategies between the positive and negative genetic susceptibility groups and comparing cognitive and emotional coping strategies between sexes with positive genetic susceptibility would give some insight into individuals' behavior when under this stressful condition.

The literature review of Chapter 2 presents an in-depth overview of AD beginning with a brief history of the disease. A brief review of the research on the four mutant genes identified as causal factors for AD are presented. A review of the terms *chronic stress* and *coping* are presented, followed by a review of the two theories and some of the research conducted using each of the theories. In Chapter 3 a detailed description of the methodology used and a full description of the assessment instrument and the reliability of the instrument are presented. The design of the study and the method of obtaining participants for the study is explained. In Chapter 4 the results of the study are presented. In Chapter 5 the discussion, interpretation of the findings, limitations of the study, recommendations, implications for social change, and conclusion are presented.

Chapter 2: Literature Review

Introduction

In this literature review, I identified the need to research the different coping strategies used by people who, based on genetic testing, have positive or negative genetic susceptibility test results for developing AD. LOFAD and LOAD are the two types of AD on which most research has focused. In the past, AD was identified only after advanced symptoms of AD appeared or via a postmortem (Vernarelli et al., 2010). Genetic discoveries within the last 15 years have made it possible to identify the mutant genes considered as causal factors and associated with the development of AD before the disease's onset (Blennow et al., 2006).

Limited research has been conducted about the psychological impact on individuals who know they carry a mutant gene associated with developing AD and the coping strategies used to live with that knowledge. Some people may view knowledge of positive or negative genetic susceptibility test results for AD as a chronic stressor. The knowledge may affect their everyday coping strategies. Men faced with this knowledge may use different coping strategies than do women (Chipperfield et al., 2007). Chipperfield et al. suggested sex plays a role in selection of day-to-day coping strategies used by men and women. Current literature supported the notion that research of coping strategies between individuals with positive or negative genetic susceptibility test results be examined and that coping strategies used between sexes with positive genetic susceptibility test results be examined (Chipperfield et al., 2007; Fanshawe et al., 2008; Gooding et al., 2006; Linnenbringer et al., 2010; Vernarelli et al., 2010).

The current study was based on two coping models: Rothbaum et al.'s (1982) primary and secondary control model, and the stress appraisal and coping model of Lazarus and Folkman (1984). These two models have been identified as being used most often to explain how individuals cope under chronic stress (Skinner et al., 2003). Research in the literature review supported the supposition that a chronic stressor can affect coping strategies (Wadsworth & Compas, 2002). The research also supported the idea that sex plays a role in the type of coping strategies an individual selects (Chipperfield et al., 2007). However, a gap in the literature existed regarding how positive or negative genetic susceptibility test results for AD affects the use of coping strategies beyond the 12 months following test results. A further gap in the literature existed as to the relationship of sex in the selection of coping strategies based on positive genetic susceptibility test results. The present research closed these gaps. The present research also adds to the current literature about the types of coping strategies (cognitive or emotional) used by these individuals. The research adds information on the relationship of sex on the selection of cognitive or emotional coping strategies

Literature Search

I conducted a search using the following online databases and websites: PsycARTICLES, PsycINFO, MEDLINE, CINAHL, New York City Chapter Alzheimer's Association, Alzheimer's disease Information and Resources, and the National Institutes of Health. The following words and terms were used in different combinations; *coping, stress-coping, repression-sensitization, model of perceived control, stress, appraisal and*

coping, primary and secondary control, Alzheimer's disease, dementia, presenilin 1, presenilin 2, apolipoprotein E, neurofibrillary tangles, amyloid beta, and *REVEAL.*

I searched for articles in the years 2002 through 2012 as well as browsed peer-reviewed literature in the following journals: *Journal of Aging Health, Psychology and Health, Journal of Personality and Social Psychology, Psychology Bulletin, Journal of Social and Clinical Psychology, Journal of Alzheimer's Disease,* and *Genet Med*. There was little research on coping behaviors and sex differences based on genetic susceptibility test results found in the current literature. The closest studies that addressed changes in health behavior based on sex were conducted by Chipperfield et al. (2007). Research studies conducted by the REVEAL (2000– 012) projects were included as part of the sparse current research literature related to coping behaviors, such as anxiety, depression, and dietary changes. In addition, studies on chronic stress based on health issues and other research based on health issues were also included. It was suggested by Hiraki et al. (2009) and Linnenbringer et al. (2010) that chronic stress had been linked to genetic susceptibility testing.

This chapter presents a review of the literature on AD. The terms *chronic stress* and *coping* are defined and explained. How chronic stress and coping affect everyday life is reviewed through the literature. Current research examining coping behaviors for chronic stress conditions and how psychological and physical health is affected are examined through literature review as well. The two coping theories were explored through the literature. The chapter concludes with a brief summary of the literature presented throughout the chapter.

Alzheimer's disease

AD, as reported by Bird (2009), is one of the most common forms of dementia. AD is divided into two categories based on age of onset: late onset and early onset AD (LOAD and EOAD, respectively). According to Bird these categories are further divided into types based on the presence or absence of genetic factors and age of onset: late onset familiar AD (LOFAD) and early onset familial AD (EOFAD). In LOFAD and EOFAD the presence of defective gene/genes are found within the family; they can be inherited from a parent or second degree relative (Papassotiropoulos, Streffer, Hock, & Nitsch, 2001).

AD is a disease that has a slow progression and is presently incurable, neurodegenerative. and terminal (Papassotiropoulos et al., 2001). According to Bird (2009) the disease's silent progress produces signs that include cognitive impairment and problems with judgment, decision-making, and orientation. According to Bird, these signs are coupled with instrumental signs such as aphasia, apraxia. and agnosia; the general loss of body functions eventually leads to death. Bird reported the disease's progress may take place over an indeterminate period of time, as long as 10 to 20 years or more before clinical signs may appear. Blenow deLeon and Zetterberg (2006) reported AD pathogenesis consists of neuritic plaques—made up of β-amyloid peptide (Aβ)—and neurofibrillary tangles)—made up of hyperphosphorylated tau. The plaques and tangles form in the brain causing brain tissue deterioration resulting in instrumental and cognitive function loss. In EOFAD and EOAD cases, the presences of plaques and tangles are more profuse than in LOFAD and LOAD cases (Blennow et al., 2006).

The history of AD begins with the discovery by Alzheimer (1907) of the plaques and tangles in the brain tissue of his patient Auguste Deter who was 54 years old (Goedert, 2008). According to Hippius and Muller (2008), Alzheimer presented his findings in 1907 at a symposium to a less than interested audience. Goedert reported that during that time, Fischer (1907) discovered the same plaques and tangles in the brain tissue of 12 patients over the age of 65. Ballenger (2006) reported that Emil Kraepelin, the chair of the psychiatry department at the University in Munchin and Alzheimer's coworker, published Alzheimer's findings in his textbook *Clinical Psychiatry: A Text-Book for Students and Physicians*. Kraepelin (1910) named Alzheimer's findings in the textbook *Alzheimer's Disease* (Ballenger, 2006).

The terms *AD* and *senile dementia* were used separately to describe early onset and late onset AD, respectively, until the early to mid-1970s (Ballenger, 2006). Lage (2006) reported Blessed, Tomlinson, and Roth conducted research using two groups of patients: one group consisted of senile dementia patients and the other group consisted of AD patients. Following the death of each patient, an autopsy was performed, and it was found that plaque and neurofibrillory tangles were present in patients in both groups. Older patients diagnosed with "senile dementia had AD" (Lage, 2006, p. 20). Katzman (1976) wrote the editorial for the *Archives of Neurology* in which he reported the findings of Blessed et al., and other researchers who following Blessed et al. also found older patients diagnosed with senile dementia to have the same plaque and tangles as patients with AD (Lage, 2006). It was not until 1977 when the National Institute for Health (NIH) held its first meeting on AD that the term senile dementia was replaced with the term AD.

EOFAD and EOAD are the ascribed names given to individual whose onset is before age 60 (Papassotiropoulous et al., 2001). LOFAD and LOAD are the ascribed names given to individuals whose onset is after age 65.

Until 1992 to 1995, little was known about the cause of EOFAD, EOAD, LOFAD, or LOAD. According to Lage (2006), it was in 1991 when Pericak-Vance et al. (1991) identified the apolipoprotein E (APOE4) gene on Chromosome 19 as the cause for susceptibility to LOFAD and LOAD in both familial and sporadic form. Sherrington et al. (1995) isolated the gene on Chromosome 14 that was identified as the gene responsible for 80% of EOFAD and EOAD (Steiner, 2008). Several months after the Sherrington et al. discovery, G.D. Shellenberg et al. located the gene on Chromosome1 that accounted for the remaining 20% of EOFAD and EOAD (Tanzi & Parson, 2000, p. 181). According to Avila-Gomez, Jimenez-Del-Rio, Lopera-Restrepo, and Velez-Pardo (2008), a third mutant gene, the amyloid precursor protein (APP) gene, was discovered by Glenner and has been found to be associated with EOFAD and EOAD.

Alzheimer's disease Studies

According to Hiraki et al. (2009), ethnicity, ethics, psychological impact, disclosure, education, and gender have been key issues the REVEAL studies have focused on in the last few years. The REVEAL study is an ongoing study of the effects of genetic susceptibility testing for AD and the effect of positive susceptibility results on psychological behavior in individuals who are children or siblings of AD patients. The studies were conducted at several locations including Boston University School of Medicine, Weill Medical College of Cornell University and Case Western Reserve

University, Brigham and Women's Hospital, Howard University, University of Michigan, University of Pennsylvania, and the National Institute on Aging (NIA). The studies have been sponsored by the NIH; to date, there have been four REVEAL series of studies beginning with Reveal I from 2000 to 2004, Reveal II from 2003 to 2006, Reveal III from 2007 to 2010, and Reveal IV starting in 2010, which is ongoing (Hiraki et al., 2009). In each of the REVEAL studies, the participants were provided with an educational protocol, given one-on-one genetic education sessions with a genetic counselor, and took part in a general question and answer session. The participants were told about certain vitamins (Vitamin E) and medications that were being investigated that might lower cholesterol and delay or prevent AD. The participants were also told that to date, no vitamin or medication has been proven effective in preventing AD.

Christensen et al. (2008), as part of the REVEAL III project, studied the ethical and ethnic issues involved in creating a genetic testing model for African Americans and for developing a protocol for disclosing genetic information. The researchers included an ethical and ethnic protocol into the AD genetic assessment. The method used by the researchers was the review of epidemiological data from the REVEAL study, and data from the Multi-Institutional Research in Alzheimer's Genetic Epidemiology (MIRAGE) study (Christensen et al., 2008). The MIRAGE study researched the role of genetic factors in the development of AD.

The MIRAGE study was a longitudinal study that included Caucasians, African Americans, and Japanese Americans and was conducted for 13 years at several locations in the United States, Canada, Germany, and Greece (Christensen et al,. 2008). The study

consisted of 2000 participants who had a first-degree relative with AD (Christensen et al., 2008). The MIRAGE study is considered to date to be "the largest genetic epidemiological study of its kind" (Christensen et al., 2008, p. 4).

Christensen et al. (2008) asked the questions, "Are African Americans at a greater risk for AD? Do genetics have the same impact on African Americans and their acceptance of genetic risk information as it does for Whites?" The data used by the researchers were the results of a national phone survey of 375 African American and 960 White Americans conducted by the MIRAGE and REVEAL studies. The results of the Christensen et al. study found African Americans were at no greater risk for AD than Whites, that genetics have the same impact on African Americans as it does White Americans, and that African Americans accept genetic risk information.

Research into health behavioral changes made by individuals who are positive for one or more of the mutant genes identified as being causal for AD, according to Vernarelli et al. (2010), has been limited. Vernarelli et al. conducted research sponsored by the REVEAL III study on changes in dietary behavior and the use of dietary supplements. The research consisted of 272 participants; 193 women and 79 men, ranging in age from 54 to 58 years old, were given genetic testing. All were positive for one or more of the mutant genes associated with AD. All of the participants were given a questionnaire with eight yes or no questions on changes in health behavior 6 weeks following the genetic testing procedure. The results were that all the participants had made changes in their dietary and exercise behavior, and 16% had also made changes in using dietary supplements. The researchers found that 50% of the participants after

disclosure included vitamins and natural herb supplements into their diet. Vernarelli et al. also found that younger participants were more likely to make dietary changes than were older participants, and although this finding was not statistically significant, women were more likely to make dietary changes. These researchers suggested that further studies need to be conducted into health behavior changes.

Current research projects such as REVEAL have only included studies related to positive genetic susceptibility testing based on educational and counseling protocols, dietary changes, risk perception, health behavior changes, and anxiety and depressive behavioral changes. The strength of these studies is based on these being the first studies in these areas. The weakness of these studies were they did not explore or compare coping strategies between individuals with positive genetic test results and individuals with negative genetic test results; nor did they explore the differences in coping strategies between sexes with positive susceptibility test results. A further weakness of the REVEAL studies was they only covered the first 12 months following genetic testing and did not extend beyond 12 months.

Chronic stress is one of the main reasons for employing coping strategies (Hiraki et al., 2009). There are many reasons for an individual to develop chronic stress. In the following discussion, I define the term *chronic stress*, review causes of chronic stress, and describe several research studies on the physical and psychological effect of chronic stress.

Chronic Stress and Coping

Chronic stress is a physical or psychological strain that has a slow onset and long duration; it can result in health or psychological problems or both (Marin et al., 2007). Chronic stress can be caused by situations involving family, health, perceived threats of physical or psychological abuse, perceived risk, perceived loss, fear of death and dying, and perceived health issues that can lead to disability or death (Monroe et al., 2007). Studies on major depression have produced evidence of chronic stress being a factor (Monroe et al., 2007). One such study was conducted by Monroe et al. (2007) on life events that cause chronic stress, its impact on major depressive episodes, and its recurrence. The research questions asked by Monroe et al. were whether chronic stressors are associated with episodes of depression and the reoccurrence of depression. The authors used a sample of 96 adult participants, ages 18 to 58 years old, 71 women and 25 men; all had been diagnosed with major depression and had at least two depressive episodes. The participants were assessed using the Life-Stress Assessment (LED) developed by Brown and Harris (1989), which is used to measure life stress.

Monroe et al. (2007) found that chronic life stressors are positively correlated to major depressive episodes. Monroe et al. found that chronic stressors were associated with episodes of depression and the reoccurrence of major depression. The authors also found that time of onset of the first episode of major depression and the reoccurrence of major depression were positively correlated with time of chronic stressor onset. Monroe et al. posited that early, unresolved stressful events in life can carry over into the individual's current daily life, creating a situation of chronic stress. The research authors

pointed out that major depression can cause a person to be unable to function within his or her environment and to withdraw from his or her family and social relationships. Furthermore, Wadsworth and Compas (2008) found that chronic stress is positively linked to psychological dysfunction and morbidity.

Chronic stress has been linked to genetic susceptibility testing for AD. Hiraki et al. (2009), as part of the REVEAL III project, conducted a study on genetic risk perception for AD. Hiraki et al. hypothesized that the participant's family history of AD would affect their risk perception, which would be heightened by those who believed genetics testing for AD to be an important factor. The researchers examined the impact of positive testing results presented in a compact clinical protocol. The protocol contained educational and counseling information and was presented by a genetic counselor who had been trained in the protocol. The study participants consisted of 293 participants, 208 women and 85 men, ages ranging from 45 to 59. The independent variables consisted of demographic information such as age, gender, socioeconomic status, and education. The dependent variables in the study were family history and AD causation perception. A mail survey was conducted at intervals of 6 weeks, 6 months, and 12 months post disclosure. The results of the study were that family history was an important factor in risk perception and that younger participants reported genetic testing was an important factor. The participants' perceived risk influenced the participants' coping strategies and behavior. Hiraki et al. also reported that an individual's knowledge of having susceptibility for developing AD in the future based on positive genetic test results can create a chronic stress condition.

Studies into perceived threat of susceptibility for AD and stress have been conducted using testing of recall and interpretation of genetic testing results for APOE4 genotype (Linnenbringer et al., 2010). Linnenbringer et al. as part of the REVEAL project conducted a study testing two hypotheses:

a. that accurate recall of risk estimate for AD would be different from the individual's perceived risk, and
b. that gender, age, education, and health concerns would affect recall and perceived risk.

Linnenbringer et al. based their study on prior studies that suggested stress, personal experience, gender, age, concerns about disease, cognitive factors, education, and emotional factors affect perceived risk and recall (d'Agincourt-Canning, 2005; Huiart et.al., 2002; Kelly et.al., 2005; Madlensky, Flatt, Bardwell, Rock, & Pierce, 2005; Sivell et.al., 2008). The study consisted of 246 adults who were over 18 years old and had at least one first-degree relative with AD. The participants after receiving their genetic test results were given a follow-up survey at intervals of 6 weeks, 6 months, and 12 months. The surveys consisted of questions about the participant's ability to recall his or her risk assessment estimate, the participant's ability to prevent AD, the participant's ability to limit AD, and the participant's ability to control the development of the disease. The participants were also assessed using the Beck Anxiety Inventory (BAI; Beck & Steer, 1993), which assessed the participants' level of anxiety.

Out of the 246 participants, 158 participants completed the full study, and the results were based on these 158 participants (Linenbringer, 2010). All participants

accurately recalled their risk estimate scores. There were differences in recall of the risk estimate and the individual's perceived risk. At the 6-week period, 53% of the participants reported a decrease (low) in perceived risk under the risk estimate; these statistics remained constant over the 6-month and 12-month period. The remaining 47% of the participants reported an increase (high) in perceived risk. The statistics remained constant over the 6- and 12-month period, over scoring the risk estimate by as much as 20 points. The authors reported in the low group the participants believed they had control over AD and did not report increased stress. In the high group, the participants believed they had no control over AD and reported increased stress levels. Linnenbringer et al. suggested repression of undesirable information by distortion of reported risk estimates was based on whether the participant believed he or she had control over the prevention or development of AD. For the variables gender, age, education, and health concerns, results showed that these variables were not significant factors in perceived risk and recall.

Chronic stress has been positively related to depressive disorders, anxiety disorders, and substance abuse (Monroe et al., 2007). Denson, Spanovic, and Miller (2009) reported there is a large body of research evidence confirming the detrimental effect of chronic stress on health. Ashida et al. (2010), as part of the REVEAL project, conducted research on the psychological impact of genetic testing and sharing the results of the genetic testing with others. These investigators reported that symptoms of depression and anxiety have been reported along with testing distress. The investigators hypothesized that as the perceived risk for AD increased so would symptoms of

depression and anxiety, and that sharing results with others would decrease depression and anxiety symptoms. The study consisted of 269 adults under the age of 65 who were identified as carriers of one or more of the mutant genes known to be casual factors for AD.

The participants completed the following questionnaires: the Center for Epidemiology Studies-Depression scale (CES-D) developed by Radloff (1977); the BAI developed by Beck, Epstein, Brown, and Steer (1988); the Impact of Genetic Testing for AD (IGT-AD), which was based on the multidimensional impact of cancer risk assessment questionnaire developed by Cella et al. (2002). The participants were given the questionnaire 6 weeks after receiving the test results, then again 12 months later. The results of the research were the participants exhibited high levels of depression and anxiety as well as high levels of test distress at 6 weeks and higher levels at 12 months. It was found that sharing the information with friends or health professionals helped decrease the participant's depression level. Ashida et al. (2010) suggested that coping with information about health issues such as AD can cause chronic stress and can affect coping strategies. None of the aforementioned studies had explored coping strategy differences between groups with positive genetic test results with that of negative genetic test results, or coping strategy differences between sexes with positive genetic test results.

Coping is defined as both cognitive and emotional behavioral attempts used by an individual to change, master, modify, reduce, tolerate, regulate, or minimize an internal or external stressful event (Skinner et al., 2003). According to Howerton and Grundy (2009), coping is a complicated process that is influenced by many factors: personality,

the situation, social and physical factors, sex, and age. Coping often requires the individual to appraise and reappraise the stress situation and decide what coping strategies to use before acting. Heppner (2008) reported coping is not an automatized behavior but requires thought and actions on the part of the individual. Skinner et al. (2003) suggested coping allows the individual to remove or limit the stressful situation or the emotional components that accompany the stressor; the individual may withdraw, engage, or do nothing about the situation. Under the term *coping*, there are many coping strategies and forms of coping behaviors/responses that may be employed by an individual; these include problem-focused, emotional-focused, avoidance, primary-coping, secondary-coping, disengagement, planning, seeking social support, and gathering information (Skinner et al., 2003).

Groomes and Leahy (2002) reported there are several coping models and that most coping models/strategies are based on either the interactionist model (Blumer, 1969) or the transactionist model (Lazarus & Folkman, 1984). These authors cited Endler (1997) who reported that in the interactionist model, the environment and the individual affect coping (unidirectional); in the transactionist model the interaction between the individual and the environment affects all directions. Individual differences often mediate coping styles. The individual's relationship with his or her environment, in which the perceived threat occurs and the level of the perceived threat, helps the individual determine the type of coping strategies he or she will use (Hock & Krohne, 2004). According to Howerton and VanGrundy (2009), coping styles differ between genders;

these differences have produced mixed evidence as to the types and style of coping preferred by the individual.

There are many coping strategies: problem-focused, emotional-focused, primary coping, secondary coping, avoidance, disengagement, seeking social support, and withdrawal (Skinner et al., 2003). The intensity of the stressor/chronic stressor mediates the coping strategy/strategies used by the individual (Groomes & Leahy, 2002). Coping styles differ between genders (Howerton & VanGrundy, 2009). Perceived risk influences an individual's coping strategy and behavior (Hiraki et al., 2009).

Fanshawe et al. (2008), as part of REVEAL III, conducted a study examining behavior changes based on APOE-4 disclosure. The researches hypothesized there would be a change in behaviors based on positive APOE-4 results and little change in behavior based on negative APOE-4 results. The research variables were age, gender, and family history. The research consisted of 162 men and women who had either a parent or sibling diagnosed with AD. The participants were placed into two groups: an intervention group of participants who had been given their genetic test results (positive or negative) and a control group who were given supposed risk assessment of their genetic test results. The participants were given a self-report questionnaire 12 months after the genetic disclosure. The questions asked on the questionnaire related to behavioral changes in diet, exercise, and vitamin intake.

Fanshawe et al. (2008) found there were changes in behavior of the participants who received positive genetic test results. In the positive test results intervention group, 53% changed behavior in the form of changing his or her diet, doing more physical

activity, and increased use of vitamin supplements, while in the control group only 31% changed his or her behavior in diet, physical activity and diet supplement use. Participants in the negative test results intervention group produced a 24% behavioral changes in diet, physical activity, and in the use of diet supplements. The researchers concluded behavioral changes were greater when the test results for genetic testing for AD are positive. The researchers did not report the results for the variables age, gender, or family history. There has been exclusion of information related to age and gender in numerous REVEAL studies (Ashida et al., 2010; Christensen et al., 2008; Hiraki et al., 2009; Vernarelli et al., 2010). Although important research questions related to genetic susceptibility for developing AD have been explored by the researchers in the REVEAL studies, the exclusion of data related to age and gender or comparison of coping strategies has been a weakness in the REVEAL studies.

Two main coping theories have been developed over the past 47 years: the primary and secondary control theory of Rothbaum et al. (1982) and the stress, appraisal, and coping theory of Lazarus and Folkman (1984). Skinner et al. (2003) posited that these two models are made up of cognitive and emotional behavioral components. The following discussions cover the two coping theories.

Coping Theories

Primary and Secondary Control

Rothbaum et al.'s theory of primary and secondary control has its foundation in the theory of perceptions of uncontrollability (Zeidner & Endler, 1996). According to Zeidner and Endler (1996), the theory of perceptions of uncontrollability was developed

by Wortman and Brehm and posited that an individual's inability to control an event can lead to reactance or an increase in an attempt to regain control over the event. Zeidner and Endler reported that during the late 1970s and 1980s, extensive research was conducted testing the theory in the areas of traumatic events and victimization by numerous researchers (Burgess & Holmstrom, 1979; Frieze, 1983; Horowitz, 1983; Janoff-Bulman & Timko, 1979; Van Dijk & Steinmetz, 1979). According to Zeidner and Endler, Rothbaum et al. theorized that behaviors viewed as a loss of control or as reflecting a sense of helplessness actually help to retain the perception of control. Rothbaum et al.'s theory, according to Zeidner and Endler, added a second process, that of secondary control—the individual attempts to fit into his or her environment.

According to Haynes, Heckhausen, Chipperfield, Perry, and Newall (2009) the theory of primary and secondary control has been used in research studies over the years in areas of health and psychological distress. Current literature supports the idea that primary and secondary control coping strategies may be used by an individual with positive genetic susceptibility test results by either attempting to change the possible outcome of their test results (primary control) or by accepting/fitting into the possible outcome (secondary control; Marteau, Roberts, LaRusse, & Green, 2005; Masters & Walston, 2005). Skinner et al. (2003) classified primary control as a cognitive response and secondary control as an emotional response.

Primary control, as reported by Skinner (2007), was defined by Rothbaum et al. as the attempt by the individual to change his environment/stressful situation so as to fit the individual's needs; primary control attempts to influence the condition/event or alleviates

the symptoms of the stressor. According to Skinner, Rothbaum et al. defined secondary control as the attempt by individuals to fit in, assimilate, or accommodate to their environment/stressful situation. Skinner posited that secondary control permits the individual to accept circumstances and events the individual cannot control. According to Lim and Ang (2006) the main theories of control in psychology are based on primary control (internal locus of control). Individuals with high internal locus of control believe they can control their environment, exhibit better coping skills, do better in school, work, social environment, and have more social support (Lim and Ang, 2006).

The term secondary control, when introduced by Rothbaum et al. as reported by Skinner (2007), was distinguished as an adaptive process that is different from having control over all outcomes. It was presented as a positive strategy that encompassed many positive adaptive coping strategies. Morling and Evered (2006), in an effort to define secondary control, examined the different definitions used by the two disciplines that have formed under secondary control—personality psychology and health or clinical psychology. Morling and Evered postulated that under personality psychology, secondary control is described as a strategy used by an individual to adjust to the environment by accepting aspects of his or her situation within the environment. These authors posited under health or clinical psychology, secondary control is described as a strategy used by an individual to help cope with situations such as illness, disaster, loss, developmental problems, and achievement difficulties. Haynes et al. (2009) reported primary-control strategies are adjusted to accommodate adjusted primary goals, and if unsuccessful, the

individual then resorts to secondary-control strategies to help the individual to adjust and obtain new primary goals.

Primary coping has been reported by Lim and Ang (2006) as a Western coping strategy that is better suited to Western cultures that place value on individualism and individual control. The authors posited secondary control is more of an Asian coping strategy and better suited to Asian cultures that value a collective society. Lim and Ang suggested that individuals who use secondary control seek help more often when faced with stressful situations, and that individuals who seek help live better lives and are better adjusted.

Lam and Zane (2004), and Morling and Fiske (1999) as cited by Morling and Evered (2006), found primary and secondary-control coping strategies used by different cultures, ages, and sexes, to be linked to human development. Morling and Evered cited the- life-span theory of control of Heckhausen and Schulz (1995), which suggested that secondary-control's purpose is to regulate the person's emotional behavior in connection with the person's primary-control. The authors further suggested that an individual utilizes primary and secondary-control throughout the life-span with secondary-control being used as the connection that recovers lost primary-control. Morling and Evered further posited that secondary-control is reported to restore and promote motivation that leads to primary control being re-established. According to Morling and Evered secondary-control operates within two different categories, selective secondary-control and compensatory secondary-control. Selective secondary-control helps keep the individual centered on his or her primary goals; compensatory secondary-control enables

the individual to reestablish motivation and regain primary-control (Morling & Evered, 2006).

Age, sex, wellbeing, and health related research has been conducted using primary and secondary control coping styles (Chipperfield, Campbell, & Perry, 2004; Chipperfield et al., 2007; Masters & Wallston, 2005). Chipperfield et al. (2007) reported that age was a determining factor in the choice of using primary or secondary control. Chipperfield, Campbell, and Perry (2004), and Chipperfield et al. (2007) reported as individuals age and based on sex, they use secondary control strategies more than primary control strategies. Chipperfield et al. (2004) and Chipperfield et al. (2007) reported that men and women use different coping strategies when faced with health issues. These authors reported that primary control was used less often by women who faced chronic health issues. Chipperfield et al. (2007) and Masters and Wallston (2005) reported that as the women aged secondary control was used more often. The authors asserted that the use of secondary control allowed the women faced with chronic health issues to regain a sense of control over their health issue, and to regain their motivation. The researchers reported these women experienced fewer hospital visits.

One of the focuses of the current study was sex related coping: are there differences in coping strategies between sexes based on positive genetic susceptibility test results? Currently, genetic susceptibility studies have not focused on sex differences in coping. According to Green (2007) the large percentage of females in the research pools of the REVEAL studies have caused concern as to the effect this might have on future REVEAL studies (Green, 2007; Roberts et al., 2011). The current study may help

to lessen this concern and supplement prior findings of differences in coping strategies between sexes.

Primary and secondary control coping styles used by college students under a perceived health locus of control conditions was researched by Masters and Wallston (2005). The research consisted of 659 college students 68% were female and 32% were males. Each participant completed five self-report assessments: the Multidimensional Health Locus of Control (MHLC) by Wallston, Stein, and Smith (1994) and Wallston, Wallston, and DeVellis (1978); the God Locus of Health Control (GLHC), by Wallston, Malcarne et al. (1999); the Brief COPE Inventory (BCI), by Carver (1997); the Positive and Negative Affect Schedule (PANAS), by Watson, Clark, and Tellegen (1988); and the Rokeach Values Survey (RVS), by Rokeach (1973). The MHLC measured the individuals' perception of control of their health; the GLHC measured the individuals' belief in God having control over their health; the BCI measured the individuals' coping abilities; the PANAS measured the individuals' affect; and the RVS measured the individuals' terminal values/health values and instrumental values.

The results of the Masters and Wallston (2005) study were, when the student believed he or she had control over an appraised threat (health issue), the students engaged in active coping strategies (primary control). When the student believed he or she did not have control over an appraised threat (health issue) the student was passive and used secondary control coping strategies. The researchers report these findings help to explain primary and secondary control as it relates to health locus of control. According to Marteau et al. (2005) (REVEAL II project), health threats can affect an

individuals' perception. When a health threat is perceived to be uncontrollable there are greater concerns and secondary control is employed (Marteau et al., (2005). An individual may perceive a greater threat according to Marteau et al. when the health threat is based on genetic risk factors associated with susceptibility testing for AD.

The authors posited that the presence of one or more mutant genes associated with AD is normally considered to be uncontrollable. Further postulated by the authors was when a health threat is perceived to be controllable there are less concerns and primary control is employed. Marteau, et al. (2005) have acknowledged the presence of mutant genes associated with positive susceptibility test results for developing AD in the future, can be perceived as a health threat.

Currently, there are no research studies using the Rothbaum et al. (1982) theory of primary and secondary control addressing the use of coping strategies based on genetic susceptibility test results. Furthermore there are no research studies using the Rothman et al. theory addressing the use of coping strategies between sexes with positive genetic susceptibility test results, for developing AD. The Rothbaum et al. theory of primary and secondary control is well suited to research coping strategies used by individuals who have positive genetic susceptibility test results AD. The theory has been used in the past to examine coping behaviors related to stress, life threatening situations, chronic health issues, wellbeing situations, and differences in coping strategies used by males and females related to health issues.

Lazarus and Folkman's (1984) developed the theory of stress, appraisal, and coping which is similar to the theory of primary and secondary control by Rothbaum et

al. (1982). The Lazarus and Folkman theory identified problem focused coping as a cognitive coping skill similar to primary control and emotion focused coping as an emotional coping skill similar to secondary control.

Stress, Appraisal and Coping

Lazarus and Folkman (1984) theory of stress, appraisal, and coping has its foundation in the transactional theory. According to Lazarus and Folkman the transactional theory was developed by Berne. Lazarus and Folkman reported the transactional theory views coping as a process that is ongoing, and changes as the individuals' environment changes. Lazarus and Folkman identified two processes which occur within the person environment relationship: cognitive appraisal and coping. Cognitive appraisal according to Lazarus and Folkman is the process of identifying and classifying a stressful event and its' significance to the persons' wellbeing. Coping according to Lazarus and Folkman is the process of managing the person environment relationship, and the emotions that are created by that relationship. The authors posited that coping changes are based on situational demands. The demands occur because of the new rational meaning given to the situation based on the individuals' new perception of his or her environment.

According to Zeidner and Endler (1996) a number of research studies testing the Lazarus and Folkman (1984) theory were conducted during the early 1990's in the areas of stress, life-threatening situations, job related stress, and health and wellbeing. Current research supports the proposition the Lazarus and Folkman theory is an acceptable theory for use to examine coping strategies used by individuals with positive or negative genetic

susceptibility test results, and for comparing coping strategies used by sexes with positive genetic susceptibility test results for developing AD (Cheng & Cheung, 2005; Gooding et al., 2006; Howerton & Van Grundy, 2009; Shiota, 2006).

Cheng and Cheung (2005) conducted a study on individual flexibility of coping strategies based on situations of stress. The study consisted of 127 participants, 48 men and 79 women with an average age of 21 years old. Four assessment tools were used in the study: participants were assessed using the Extended Miller Behavioral Style scale (EMBSS), by Cheng, Chiu, Hong, and Cheung (2001); the State-Trait Anger Expression Inventory-2 (STAXI-2) by Spielberger (1988); the Marlowe-Crowne Social Desirability scale (MCSD) by Crowne and Marlowe (1960); and the Beck Depression Inventory (BDI) by Beck, Ward, Mendelson, Mock, and Erbaugh (1961). The EMBSS was used to measure the participants coping strategies based on hypothetical stressful events; the STAXI was used to measure general feelings and anger; the MCSD was used to measure social desirability; and the BDI was used to assess depressive feelings. Cheng and Cheung reported the results as followed: the use of cognitive appraisal allows the individual to assess the situation, and adjust to any changes in the environment, or the stressor. The authors posited that individual differences played a large part in how the individual assessed the situation, and coped with the stressful situation. According to the authors some individuals used multiple coping strategies, while other individuals used the same strategy in all stress situations.

Problem focused and emotion focused coping strategies are according to Connor-Smith and Flachsbart (2007) identified by Lazarus and Folkman (1984) as two forms of

coping. The authors reported problem focused coping as the process of actively doing something to alleviate the stressful event, or alleviating a stressful event by learning and developing new behaviors. Connor-Smith and Flachsbart asserted that the new behavior is used to influence, or change the direction of the source of the stressor, to overcome the stressor by learning new skills, and finding alternative ways of behaviors. Glass, Flory, Hankin, Kloos and Turecki (2009) cited Lazarus and Folkman as having reported that problem focused strategies involve embracing behaviors to help surmount the stressful situation. Glass et al. further reported problem focused coping is considered to be adaptive, related to positive adjustment, emotional, and physical well-being. Problem focused coping strategies according to Groomes and Leahy (2002) are used most often by people who feel they have control over, or can control the stressful event. Skinner et al. (2003) classified problem focused coping as a cognitive response to a stressful situation and emotional-focused coping as an emotional response to a stressful situation.

Howerton and Van Grundy (2009) conducted a survey examining three types of coping styles: problem focused, emotional focused, and avoidance focused, used by men and women under situations of stress. The researchers focused on gender differences in coping styles in their survey of 1,803 young adults, 956 males and 847 females. The average age of the participants ranged from 18 to 21 years old. The participants were assessed for depression using the Center for Epidemiological Studies Depression (CES-D), developed by Radloff (1977). Coping styles were assessed using the Endler and Parker (1990) measure of coping styles questionnaire. Howerton and VanGrundy reported there were no difference in the use of problem focused coping strategies

between men and women. The researchers also reported problem focused coping as an effective coping strategy that can decrease stress, and lessen depression caused by chronic stress. Kim et al. (2007) asserted that problem focused coping can affect mental and physical health favorably by helping to limit, or decrease stressful situations. Problem focused coping causes the individual to focus his or her attention on the problem, and to exert his or her energy in a constructive manner to act on the negative event (Kim et al., 2007). Research into the effect of problem focused coping on positive affect by Ben-Zur (2009) and Shiota (2006) found problem focused coping was positively linked to positive affect. The Ben-Zur study tested four hypotheses: whether problem focused coping was positively related to positive affect, or negatively related to negative affect, whether emotion/support coping was positively related to negative affect, and negatively related to positive affect, whether avoidance coping was positively related to negative affect and negatively related to positive affect, and whether elevated emotional/support, avoidance coping, and elevated problem focused coping will cause a raise of positive affect, and a decrease of negative affect. The researcher used data collected from three non-published studies on positive affect and wellbeing conducted by Ben-Zur (2002a), Ben-Zur (2003), and Ben-Zur and Reshef-Kfir (2003) that used the same assessment tools in each study, but had different purposes. The combined number of participants from all studies was 480, 52% were women and 47.6% were men, ranging in age from 16 to 82 years old. Each participant was assessed using the COPE scale, developed by Carver, Scheier, & Weintraub (1989) which measures how an individual responds to stress using either problem focused coping or emotional focused coping. The

participants were also assessed using the Positive Affect Negative Affect Schedule (PANAS), by Watson et al. (1988) that assessed the participants' mood and affect.

The results of the Ben-Zur (2009) study were: problem focused coping was positively linked to positive affect and negatively linked to negative affect, emotion/support coping was positively linked to both positive and negative affect, avoidance coping was negatively linked to positive and negative affect, emotion/support and avoidance coping were found to have a weaker effect on negative affect, and problem focused coping was found to have little effect on emotion/support and avoidance coping. Ben-Zur reported the results of the research suggested that problem focused coping was an effective coping strategy and was positively related to positive affect and wellbeing. The researcher suggested that in the context of health problems, problem focused coping has been shown to have a positive effect in controlled situations. In instances of chronic health issues, (uncontrolled situations) problem focused coping has been shown to help change the meaning of the stressful situation, to help the individual reinterpret the situation, and to concentrate on reachable goals. Problem focused coping is a task focused method of coping.

Shiota (2006) conducted a study into positive coping strategies, problem solving coping strategies, and social support coping strategies. The researcher questioned whether positive coping strategies were related to wellbeing, and whether the type of stressor determined the positive coping strategy used. The study consisted of 91 participants, 53 females and 48 males, with an average age of 21 years old. The participants were assessed using the Positive and Negative Activation Schedule (PANAS), by Watson et al.

(1988) which assessed subjective wellbeing. The participants were asked to keep a daily coping diary and to record all their daily activity. Shiota reported the results of the study produced evidence suggesting that coping strategies such as problem focused coping increases positive wellbeing and engender positive self-esteem. Shiota also reported that the type of positive coping strategy used depended on the stressor.

Emotional focused coping according to Kim et al. (2007) attempts to relieve the emotional stress that accompanies a stressful situation by the use of denial. According to Kim et al. denial can have a negative impact on physical health and psychological wellbeing. According to Howerton and VanGrundy (2009) emotion focused coping is the process of attempting to change, lessen or regulate internal emotions that are the consequences of a stressful event. The authors further reported that emotion focused coping often involves active behavior such as wishful thinking, minimization of the stressful event, and behavior that may consist of denial which is considered to be a maladaptive behavior. Most often, emotional focused coping occurs when the stressful event has been appraised as being out of the control of the individual, and the individual feels he or she can do nothing to change events (Howerton & VanGrundy, 2009). According to Riolli and Savicki (2010) seeking social or outside support and using emotional expression to relieve negative emotions are considered to be emotional focused coping strategies.

A literature research study was conducted by Gooding et al. (2006) on the transactional model of stress and coping of Lazarus and Folkman (1984). The authors sought to understand how this model was used by individuals seeking genetic testing for

the susceptibility to develop AD in the future, and how the model was used to cope with positive test result information. Gooding et al. questioned whether the Lazarus and Folkman model helped the individual in his or her decision to be tested for the susceptibility for AD. The authors reported the uncertainty of the individual not knowing if he or she had a predisposition to develop the disease created a threat to the individuals' wellbeing, which then becomes a stressor. The individual uses primary and secondary appraisal to assess the level of the threat (Gooding et al., 2006). Gooding et al. (2006) posited that this threat is caused by primary appraisal. The authors described the primary appraisal process as the individual deciding if he or she is able to control the situation and then proceeding to the secondary appraisal stage. Lazarus and Folkman defined secondary appraisal as the individuals' ability to cope with the stressor and the emotions that accompany the stressor (cited by Gooding et al., 2006). According to Gooding et al. problem focused coping and emotional focused coping strategies are used by individuals seeking genetic testing for susceptibility for developing AD. These two coping strategies are also used when an individual is faced with positive genetic test results for developing AD (Gooding et al., 2006).

According to Gooding et al. (2006) the individual then proceeds to use either problem focused coping making behavior changes, searching out information to help prevent or delay the disease, or emotional focused coping, avoidance, seeking out social support, and using cognitive reframing. The authors cited Folkman and Greer who reported problem focused coping strategies were used when individuals believed they could, or had some control over the situation. Gooding et al. further cited Zakowski, Hall,

Klein, and Baum who reported emotional focused coping strategies were used when the individual believed they did not have control over the situation. The authors pointed out there is a need to understand coping behaviors used by individuals who have a potential of developing AD in the future. The authors asserted the information could be used and applied to counseling of these individuals, and to help relieve the emotional stress faced by these individuals. The authors further asserted the current limited research into coping behaviors after positive genetic test results is an area that is ripe for research. Gooding et al. concluded by reporting that genetic research studies, and genetic counseling studies need to include cognitive and emotional coping models.

Currently there is limited research using the Lazarus and Folkman theory of stress, appraisal, and coping, addressing coping strategies used by individuals who have undergone genetic susceptibility testing for developing AD. The theory has been used in the past to examine coping behaviors related to stress, life threatening situations, health issues, and differences in coping strategies used by the sexes when faced with situations of stress related to health issues. Based on the theory having been used in past researches related to health issues, the Lazarus and Folkman theory is admirably suited to research coping strategies used by individuals who have undergone genetic susceptibility testing for developing AD in the future (Cheng & Cheung, 2005; Gooding et al., 2006; Howerton & Van Grundy, 2009; Shiota, 2006). The research questions being examined by the current study seeks to add to the exiting body of literature that have researched health related stress situations using the Lazarus and Folkman theory.

Summary

The literature review presented a brief introduction and overview of AD, the four different forms of AD, and the methods used to collect the research presented in the chapter. Chronic stress was defined as a physical or psychological strain with slow onset and long duration (Monroe et al., 2007). Coping was defined as cognitive and behavioral methods used to change or reduce a stressful situation. An introduction of the two different coping theory models that might be used by individuals faced with the susceptibility for AD followed. The two theory models were presented: Rothbaum et al. (1982) primary and secondary control model, and the Lazarus and Folkman (1984) stress, appraisal and coping model, which are according to Skinner et al. (2003) composed of cognitive and emotional coping strategies.

Research conducted on behavioral strategies used by individuals who have positive or negative genetic susceptibility for possibly developing AD were presented. A research study comparing individuals with positive genetic test rests with individuals with negative genetic test results was presented (Fanshawe et al., 2008). Research studies examining coping strategies used by sex with positive genetic test results were not found during the literature search. Only one study was found that addressed the effect of coping strategies on positive genetic susceptibility test results for AD, that of Gooding et al. (2006). Given the increased research on the effect of positive genetic susceptibility test results for developing AD in the future, its effect on psychological wellbeing, and health, researchers have suggested that coping models, and sex differences in coping strategies be included in future research in genetic susceptibility testing for AD (Ashida et al.,

2010; Gooding et al., 2006; Green, 2007; Hiraki et al., 2009; Marteau et al., 2005; & Vernarelli et al., 2010). The researchers also suggested that coping behaviors based on positive genetic test results and sex differences in coping strategies are areas ripe for study.

These gaps in the literature limit psychologists and mental health professionals in their understanding and treatment of this special group. As the number of individuals affected with AD grows (Alzheimer's Association, 2011), and genetic susceptibility testing becomes more available to the general public (Zonno & Terry, 2009), the size of this special group will increase. Psychologists and mental health professionals are expected as part of their ethical responsibility to be knowledgeable of the conditions that affect their clients and to be competent in their treatment of their clients. Limited research on coping strategies used by the sexes who have undergone genetic susceptibility testing for AD makes treating this special group difficult. Findings of the current study could aid in developing best practices for treating professionals. In conclusion, psychologists and mental health professionals may find it difficult to determine their own level of competence to treat members of this special group because of the limited research currently available.

In Chapter 3, I describe the research design, variables, setting, sample, and instrumentation used to assess coping strategies, and I also explain the data analysis procedures.

Chapter 3: Research Method

Introduction

In this chapter, I describe the research method used to examine differences in coping strategies between groups who had received positive or negative genetic susceptibility testing results for developing AD in the future. The chapter also describes the research method used to examine the relationship of sex to coping strategies 12 or more months following receiving positive genetic susceptibility test results. Research has supported the findings that sex is a factor in the selection of coping strategies and that differences in coping strategies exist between male and female coping behavior (Chipperfield et al., 2004, 2007). The chapter includes a description of the study's design, participants, instrument used to measure coping strategies, data analysis, and ethical consideration.

Research Design and Approach

This quantitative, online survey study examined the relationship between coping strategies and participants with positive genetic susceptibility test results with participants with negative genetic susceptibility test results for developing AD. The study also compared sex differences in coping behaviors used by participants with positive genetic susceptibility test results for developing AD. The rationale for using a quantitative, between group, online survey design was that it allowed use of a sample of the population of interest to compare coping strategies between the groups. Another rationale was that more prospective participants were reached who met the required characteristics of the study. Using an online survey is time saving (Nesbary, 2000); the population of interest

was spread out throughout the United States. A further rationale was that all of the participants had undergone genetic testing for the APOE-ε4 gene identified as causative for susceptibility for developing AD (Green, 2007). Each participant had been given his or her test results prior to the study, with either positive or negative results for the APOE-ε4 gene (Green, 2007). Considering the privacy of the participants and sensitivity of the data, using an online survey method was less intrusive.

Research Variables

The independent variables used in this study were test results with two levels (positive and negative genetic susceptibility test results) and sex with two levels (males and females). The literature supported the supposition that testing results for positive and negative genetic susceptibility affect behavioral changes (Chipperfield et al., 2007; Fanshawe et al., 2010; Gooding et al., 2006: Linnenbringer et al., 2010; Vernarelli et al., 2010). The literature further supported the likelihood of a relationship between sex and coping and that sex is an independent variable that influences outcome (Chipperfield et al., 2004; Chipperfield et al., 2007). The dependent variables used in this study were cognitive and emotional coping strategies. For the purpose of the study, primary control and problem focused coping strategies were represented by the term cognitive coping strategies, and secondary control and emotional focused coping strategies were represented by the term emotional coping. Skinner et al. (2003) classified secondary control and emotional focused coping as emotional coping strategies. Genetically susceptible test results (positive and negative groups) as well as sex (males and females) were examined using the dependent variables cognitive and emotional coping strategies.

Methodology

Settings, Sample, and Procedure

The sample population for the online survey study was drawn from the Alzheimer's Association of New York. The target population was males and females who had undergoing genetic testing for the APOE-ε4 gene, which has been found to be associated with possibly developing AD in the future. According to Green (2007), there are approximately 1,301 participants who had been tested for the APOE-ε4 gene and were involved with the REVEAL program.

An e-mail (Appendix A) and letter of consideration (Appendix B) requesting permission to post the study were sent to EmergingMed. EmergingMed is the agency that lists studies on their TrialMatch website for the Alzheimer's Association of New York. EmergingMed was asked if they would consider posting a flyer (Appendix C) describing the study on their website and at their site locations, following Walden University Institutional Review Board's approval (Appendix D). A copy of the study's flyer was sent with the e-mail request of consideration. Walden University IRB approved the study; the research approval number is 12-04-13-0114017. I contacted the administrator of EmergingMed notifying her of Walden's IRB approval. The administrator sent a return e-mail informing me that consent to post the flyer on their network had been approved (see Appendix E). The administrator gave approval for prospective participants to engage in the survey and to contact the me online. The flyer included the name of the study, eligibility criteria, and the method of contacting me if the prospective participant was interested in being in the study.

The participants were required to have the following inclusion characteristics: must be 45 to 75 years old and had undergone genetic testing for the APOE-ε4 gene 12 months or more prior to entering the study. The participants were also required to have a first-degree relative diagnosed with AD. The method of selecting the sample was stratification. A stratification method was chosen for the survey based on the unique characteristic of the participants having been tested for the APOE-ε4 gene and having a first degree relative diagnosed with AD.

The participants were divided into two groups based on their genetic test results being either positive or negative. The population was further divided by sex, males and females. Stratification was done based on the answers to the demographic information questionnaire. Interested individuals were asked to fill out the demographic questionnaire (see Appendix F) online to determine their eligibility to participate in the survey. Eligible individuals were instructed to complete the Brief COPE scale. The completion of the Brief COPE scale fulfilled all the participant's obligations to the research. At the end of the completed Brief COPE scale, there was a thank you note from me for participating in the study and a statement that the study was complete. The participants were given an e-mail address to contact me if they had any questions about the study or the results of the study. The participant then downloaded a $10.00 gift certificate for Starbucks. The $10.00 gift certificates were given as a thank you for taking time to participate in the study. The participants exited the study by downloading the $10.00 gift certificate.

Power Analysis

The number of participants needed for the survey was determined by conducting a power analysis. Based on Cohen (1968), the ideal power analysis was determined to be .80. Based on past studies examining similar variables, the average effect size was determined to be .10; alpha was determined to be $p < .05$. Considering the effect size, the sample size estimated for each group was 140 ($n = 140$). To obtain sufficient power, the total sample size was 280 ($N = 280$). Each group consisted of 70 males and 70 females. To account for possible attrition 150 participants per group were recruited, 75 males and 75 females. The participants' demographic information such as age and gender were collected to ensure consistency between the groups.

Instrumentation and Materials

According to Carver (1997), the Brief COPE Scale is a shorter version of the COPE scale developed by Carver, Scheier, and Weintraub (1989). The COPE scale consisted of 60 self-report questions that were divided into 15 dimensions, each dimensions having 4 items per scale. The Brief COPE scale developed by Carver has 28 items and is a self-report questionnaire that was designed to measure 14 dimensions of coping responses used when an individual is under a stressful situation, primarily related to health issues. Being given a positive test result for developing AD in the future has been reported to cause a chronic stress conditions (Chao et al., 2008). The Brief COPE scale has primarily been used in health studies. Carver (2013) gave permission for the use of all the Brief COPE scale (see Appendix G).

Carver (1997) reported the Brief COPE was designed to measure the coping strategies used by adults from 18 to 89 years old, who have or are facing health problems. According to Carver (nd) two items are assigned to each of the 14 dimensions measured by the Brief COPE scale those 14 dimensions are: self-distraction, active coping, denial, planning, acceptance, self-blame, venting, substance use, use of emotional support, use of instrumental support, behavioral disengagement, positive reframing, humor, and religion. The dependent variable cognitive coping was represented on 7 dimensions they were: self-distraction questions 1 and 19, active coping questions 2 and 7, use of instrumental support questions 10 and 23, positive reframing questions 12 and 17, planning questions 14 and 25, humor questions 18 and 28, and acceptance questions 22 and 27. The dependent variable emotional coping were represented by: denial questions 3 and 8, substance use questions 4 and 11, use of emotional support questions 5 and 15, behavioral disengagement questions 6 and 16, venting questions 9 and 21, religion questions 20 and 24, and self-blame questions 13 and 26. The 28 items are rated on a four- point Likert scale ranging from 1 to 4: 1. “I haven’t been doing this at all”, 2. “I’ve been doing this a little bit”, 3. “I’ve been doing this a medium amount”, and 4. “I’ve been doing this a lot”. The two items assigned to a dimension were summed, a high score indicates a preferred type of coping (Appendix H). The Brief COPE can be administered in 10 to 15 minutes.

According to Carver (1997) the Brief COPE scale was normed using a sample of 168 participants from a community affected by hurricane Andrew in a study conducted by David et al. The sample consisted of 66% female and 34% males. The participants

were assessed 3 months after the event, 6 months after the event, and one year after the event. Carver used these assessments to evaluate the reliability of the Brief COPE scale using a factor analysis. The results of the factor analysis were 9 of the factors were greater than 1.0 they were: substance use, religion, humor, behavior disengagement, use of emotional support, use of instrumental support, active coping, planning and positive reframing. These results corresponded with the results of the original Cope scale. Two scales venting and self-distraction loaded on a single factor, and denial and self-distraction also loaded on a single factor. An item from the acceptance scale loaded "on its own factor" (p.97) with the other loading on the active coping factor at .52, with .47 as a secondary loading on the acceptance factor. These results were similar to the results of the original COPE scale.

Carver (1997) conducted a reliability analysis of the Brief COPE scale administered as part of the Hurricane Andrew study. The first assessment took place 3 to 6 months after the hurricane, second assessment 6 months after, and the third assessment a year later. Carver reported each assessment was evaluated individually for the purpose of evaluating the scales, reliability. The following alpha reliabilities are based on the three Hurricane Andrew assessments: active coping ($\alpha = .68$), planning ($\alpha = .73$), positive reframing ($\alpha = .64$), acceptance ($\alpha = .57$), humor ($\alpha = .73$), religion ($\alpha = .82$), using emotional support ($\alpha = .71$), using instrumental support ($\alpha = .64$), self-distraction ($\alpha = .71$), denial ($\alpha = .54$), venting ($\alpha = .50$), substance use ($\alpha = . 90$), behavioral disengagement ($\alpha = .65$) and self-blame ($\alpha = .69$). Carver concluded that based on these results which met a .50 value, or better the Brief COPE scale is a reliable instrument.

Carver thus reported that the test- retest reliability of the Brief COPE scale was consistent with the reliability results of the original COPE scale.

Fillion, Kovacs, Gagnon, and Endler (2002) conducted research into the validation of the Brief Cope scale by correlating the Brief COPE scale with the Coping with Health Injuries and Problems scale (CHIP) developed by Endler, Parker, and Summerfeldt (1998), and the Profile of Mood States scale (POM) developed by McNair, Lorr, and Droppleman (1971). The CHIP assesses coping strategies used by individuals with illness. The POM is used to measure an individuals' mood disturbance during illness. Fillion et al. (2002) conducted a research study consisting of 132 participants, women diagnosed for the first time with breast cancer and who were undergoing various stages of treatment. The participants completed the CHIP, POM, and the brief COPE scale. Construct convergent validity of the Brief COPE scale was examined by correlating the four scales of the CHIP with the scales of the Brief COPE scale using the factor based scores. The result of the analysis was a high correlation between the CHIP instrumental coping, the Brief COPE scale problem solving, and active coping of (r =.51, p = .01). The distraction scales of the CHIP and the brief COPE scale produced a high correlation of (r =.49, p = .01). Further there was a high correlation between the CHIP emotional preoccupation and brief COPE scale disengagement of *(*r =.64, p = .01). The results support the construct validity of the Brief COPE scale. Fillion et al. conducted a further examination of concurrent criterion validity of the Brief COPE scale.

The six subscales of the POMS were correlated with the Brief COPE scale eight factor based subscales scores to examine concurrent criterion validity. The results of the

correlation were the POMS subscales for depression, anger, and anxiety produced a high correlation with the Brief COPE scale disengagement subscale (r >.50, p =.01), fatigue, confusion and vigor produced positive correlation with the Brief COPE disengagement subscale of (r<.50, p =.01). The seven remaing subscales of the Brief COPE scale: self-distraction, active coping, using emotional social support, using emotional support, religion, humor and substance use were also found to be positively correlated with the POMS six subscales: anxiety, depression, fatigue, anger, confusion and vigor (*range* = .17 – .38, p = .01). The results supported concurrent criterion validity of the Brief COPE scale. According to Fillion et al. (2002) the results were consistent with the findings of Carver et al. (1997) and Johnson (1997) which support concurrent criterion validity of the Brief COPE scale. Following the participants' completion of the demographic questionnaire the participant were allowed to access the Brief COPE scale. The Brief COPE scale was filled out online.

Research Questions

The first research question addressed whether there are significant differences in coping strategies between the P group and the N group following genetic susceptibility test results for developing AD in the future, in the 12 months or more period after receiving test results, as measured by the Brief COPE scale.

Ho1. There are no significant differences in coping strategies as measured by the Brief COPE scale, between the (P) group and the (N) group following genetic susceptibility test results for developing AD in the future, in the 12 months or more period after receiving the test results.

Ha1. There are significant differences in coping strategies as measured by the Brief COPE scale, between the (P) group and the (N) group following genetic susceptibility test results for developing AD in the future, in the 12 months or more period after receiving the test results.

Research question 2: Are there significant differences in coping strategies by sexes as measured by the Brief COPE scale used by participants who received positive genetic susceptibility test results for developing AD in the future, in the 12 months or more period after receiving test results.

Ho 2. There are no significant differences in coping strategies by sexes as measured by the Brief COPE scale used by the participants who received positive genetic susceptibility test results for developing AD in the future, in the 12 months or more period after receiving test results.

Ha 2. There are significant differences in the use of coping strategies by sexes, as measured by Brief COPE scale used by the participants who received positive genetic susceptibility test results for developing AD in the future, in the 12 months or more period after receiving test results.

Data Analysis

Independent measure *t* tests were used as the methods of statistical analysis. The independent measure *t* test was used to compare means between two separate populations, the independent variables test results having two levels P group and N group and sex having two levels (male and female) on the dependent variables cognitive coping

and emotional coping based on scores from the Brief COPE scale. All participants had received their test results 12 months or more before entering the study.

Ethical Considerations

Participants' Protection and Rights

The protection and the rights of the participants in the study were of paramount concern to this researcher. No identifying information was obtained in this study. The information obtained in the study was solely for the purpose of answering the research questions. All participants were issued an identifying number upon entering the survey. No one other than myself had access to the test material or the completed demographic questionnaire. All data in the form of paper copies were placed in a locked file and will be kept for five years following the dissertation publication. The data were interpreted solely for the purpose of answering the research hypothesis of the study. No other interpretation was performed concerning the responses of the participants.

During the study if any participant wished to withdraw or request his or her data be removed and destroyed, the request was honored. No inquiry was made by me as to the reason for the participant's withdrawal. No such event occurred. The nature of the study did not require the participant to answer any questions that could be deemed as harmful to the participant's wellbeing.

Summary

Chapter 3 described the research design, which was a quantitative online survey. The data was analyzed using independent-measure *t* tests. The study compared mean differences in coping strategies based on genetic susceptibility test results between the positive (P) groups and the negative (N) group based on the scores obtained from the Brief COPE scale. The study also compared mean differences in coping strategies between sexes with positive genetic susceptibility test results. The chapter described the method used to gather the data to answer the research questions. The independent variables in the study were test results (positive and negative) and sex (males and females), the dependent variable was coping (cognitive and emotional). The chapter also described the special characteristics of the participants that were included in the study. The participants were required to be 45 to 75 years old and had undergone genetic testing for the APOE-e4 gene 12 months or more prior to the study. The participants were required to have a first degree relative diagnosed with AD. The participants were drawn from the clients of the Alzheimer Association of New York. A description of the Brief COPE scale, the measurement instrument that was used to answer the research questions was presented. A description of the cautions taken by me to preserve the participants' rights were described. Chapter 4 presented the results of the analysis of the data. Chapter 5 presented a discussion of the results,the implications, and impact of the results on social change.

Chapter 4: Results

Introduction

The purpose of this study was to examine the relationship of the independent variables test result (positive or negative) and sex (male and female) with the dependent variables cognitive coping and emotional coping strategies at least, 12 or more months following genetic susceptibility test results for developing AD in the future. The first null hypothesis stated there would be no significant differences in coping strategies between the test result groups P and N after genetic susceptibility test results for developing AD, in the 12 or more months after receiving the test results. The alternative hypothesis stated there would be differences in coping strategies between the two groups. The second null hypothesis stated there would be no significant differences in coping strategies between the sexes with positive genetic susceptibility test results for developing AD, in the 12 or more months after receiving the test results. The alternative hypothesis stated there would be differences in coping strategies between the sexes. Each question was measured using the Brief COPE scale. The Brief COPE scale is a 28 item self report questionnaire that was designed to measure 14 dimensions of coping responses. This chapter has several sections: the demographic characteristics of the participants, data collection time frame and response rate, assumptions of independence, normality, and homogeneity of variance, and report of the data analysis with tables.

The participants responded to the online survey by accessing a designated website and answering the demographic questions related to their qualifications, followed by the Brief COPE survey questions. The data collected to answer the two research questions

and to examine the hypotheses were analyzed using the 22.0 version of the Statistical Package for the Social Sciences (SPSS) program. The independent variables of test results and sex, and the dependent variables of cognitive coping and emotional coping were examined. A 95% confidence interval was used for all analyses with a significance level set at an alpha equal to or less than .05.

Demographic Characteristic

A flyer announcing the survey was posted for three months on the Alzheimer's Association of New York website, EmergingMed. Three hundred and twelve males and females responded over the three month period. Two hundred and eighty participants were selected: 70 positive males, 70 positive females, 70 negative males and 70 negative females, for a total of 140 male (50%) participants and 140 female (50%) participants. In Table 1 frequencies and percentages are presented. Of the 312 surveys, 32 surveys were rejected as either not meeting the criteria or for being incomplete. All 280 participants answered the demographic questions. All participants had relatives who had been diagnosed with AD. All participants were between the ages of 45 and 75 years old (see table 2), and all participants had been tested 12 or more months prior to the date of the study for the APOE-4 gene which has been associated with developing AD in the future. The data were collected and analyzed using an independent measures *t* test and analyzed using the SPSS statistical program.

Table 1

Participants Demographics: Sex, Positive by Sex, Negative by Sex, Numbers and Percentages

Participants'	n	%
Males	140	50
Females	140	50
Positive Males	70	25
Positive Females	70	25
Negative Males	70	25
Negative Females	70	25

Table 2

Participants Demographics: Age.

Age	n	Percent
Age (N=280)		
45-49	75	27%
50-54	29	10%
55-59	65	23%
60-64	24	9%
65-69	40	14%
70-74	42	15%
75	05	2%

The 28 questions on the Brief COPE scale were divided into two groups each group of questions represented a level (cognitive or emotional) of the dependent variable coping. The cognitive level was represented by questions: 10 & 23, 12 & 17, 14 & 25, 1 & 19, 2 & 7, 18 & 28, 22 & 27. The emotional level was represented by questions: 5 & 16, 6 &15, 20 24, 3 & 8, 4 & 11, 9 & 21, 13 & 26, of the Brief COPE scale (see Appendix G). Descriptive and frequency distributions statistics were conducted to determine that the response to the Brief COPE Scale questions were within range. The assumption of the independent-measures *t* test is that the instrument used to obtain the data be based on an

ordinal or continuous scale, the Brief COPE scale is an ordinal scale that uses a Likert scale from 1 to 4. The score on the Brief COPE Scale can range from 1.0 to 4.0 per question, with combined questions score ranging from 8.0 to 32.0, with a median of 16.

Assumptions of Independent-Measures *T* - Test

The independent-measures *t* test is used to compare the data of two groups to see if the two groups are different, this is done by comparing the mean of the two groups. An assumption of the independent-measures *t* test is that the participants sample should be randomly selected from the population of interest and independent of each other, the scores of one participant is not related to the scores of another participant. In the current study the participants responded to an online demographic questionnaire posted on the Alzheimer's Association of New York website, EmergingMed. Based on the completion of the online demographic questionnaire and the Brief COPE scale, the participants were randomly selected and were independent of each other, no identifying data was collected.

A further assumption of the independent two-tail *t* test is that the data is normally distributed and falls within a normal distribution. The Kolmogorov Smirnov test was conducted to determine the normality of the population in this study. The dependent variables cognitive and emotional were tested to determine if the dependent variables were normally distributed within the independent variable groups as defined under test results, positive group and negative group.

Support for the first null hypothesis was based on the *t* value of 1.97 which was determined to be the critical value based on the degree of freedom of 278 for the population of interest. The sample size of the study was large and balanced ($n1 = 140$, $n2$

= 140) for a total of $N = 280$. The larger and balanced the sample size the less threat there is to the validity of the *t* test. The results of the Kolmogorov-Smirnov test produced a box-plot showing minimal scatter of the scores for the populations of test results (positive group and negative group), for cognitive, the scores were normally distributed. The results of the Kolmogorov-Smirnov test produced a box-plot showing minimal scatter of the scores for the populations of test results (positive group and negative group), for emotion, the scores were normally distributed.

Support for the second null hypothesis was based on the *t* value of 1.97 which was determined to be the critical value based on the degree of freedom of 138 for the population of interest. The sample size of the study was large and balanced ($n1 = 70$, $n2 = 70$) for a total of $N = 140$. The larger and balanced the sample size the less threat there is to the validity of the t test. The results of the Kolmogorov-Smirnov test produced box-plot showing minimal scatter of the scores for the populations of sex (positive males and positive females), for cognitive and emotion, the scores were normally distributed.

The hypothesis that the group variances are equal for test results (positive and negative) was tested using the Levene's statistical test. At the significant level 0.05 the null hypothesis is not rejected since the value of the Levene test is less than the critical value. Therefore, it is concluded that there is insufficient evidence to claim that the variances are not equal $F(278) = 2.05$, $p = .156$ (cognitive); $F(278) = .623$, $p = .431$ (emotional). The hypothesis that the group variances are equal for sex (males and females) was tested using the Levene's statistical test. At the significant level 0.05 the null hypothesis is not rejected since the value of the Levene test is less than the critical

value. Therefore, it is concluded that there is insufficient evidence to claim that the variances are not equal F (138) = .691, p = 406 (cognitive); F (138) = 2.49, p = .115 (emotional).

Hypothesis 1

The null hypothesis stated there would be no significiant differences in coping strategies as measured by the Brief COPE scale, between the positive (P) group and the negative (N) group following genetic susceptibility testing results for developing AD in the future, in the 12 months or more period after receiving the test results.

The independent variables test results had two levels (positive and negative) were subjected to a two tail independen -measures *t* tests to compare mean differences based on the scores from the Brief COPE scale for the dependent variables cognitive coping and emotional coping. The two tail independent measures *t* test compared the means of the dependent variable cognitive coping in the positive group and in the negative group, and the mean of the dependent variable emotional coping in the positive group and in the negative group, with a significance level of $\alpha = .05$.

The two tail independent *t* test was conducted to determine if the independent variable test results (positive group and negative group) differed significantly based on dependent variable cognitive coping. The test results were significant, t (278) = 11.68; $p < .001$, d = 1.40. The 95% confidence interval for test results means ranged from 4.06 to 5.71. An examination of positive group and negative group means indicates the positive group (M = 13.75, SD = 3.7) performed significantly higher on cognitive coping 12

months or more following test results than did the negative group (M = 8.86, SD = 3.27). The two tail independent t test was conducted to determine if the independent variable test results (positive group and negative group) differed significantly based on the dependent variable emotional coping. The results were significant, t (278) = 12.31; p < .001, d 1.49. The 95% confidence interval for test results means ranged from 4.21 to 5.82. An examination of positive group and negative group means indicates the positive group (M = 13.54, SD = 3.9) performed significantly higher on emotional coping 12 months or more following test results than did the negative group (M = 8.51, SD = 3.01), (see table 3).

Table 3

Means and Standard Deviation and Statistical Information for Test Results and Cognitive Coping and Emotional Coping

		Positive	Negative			95%C1		Cohen's
Coping	n	M (SD)	M (SD)	*t* (278)	*p*	LL	UL	*d*
Cognitive	140	13.75 (3.7)	8.86 (3.27)	11.68	<.001	[4.06-	5.71]	1.40
Emotional	140	13.54 (3.7)	8.51 (3.01)	12.31	<.001	[4.21-	5.82]	1.49

These findings indicated there are significant differences in coping strategies as measured by the Brief COPE scale between the positive (P) group and the negative (N)

group following genetic susceptibility test results for developing AD in the future, in the 12 months or more period after receiving test results. The null hypothesis is rejected.

Hypothesis 2

The second null hypothesis stated there are no significant differences in coping strategies by sex as measured by the Brief COPE scale used by the participants in the 12 months or more period after receiving test results. An independent measured *t* test was conducted to answer the second research question: if there are differences in coping strategies between the independent variables sex (positive males and positive females) and the dependent variables cognitive coping and emotional coping.

The two tail independent measures *t* test was conducted to determine if the independent variable sex (positive males and positive females) differed significantly based on dependent variables cognitive coping. The results were not significant t (138) = .520; p = .6, d = 0.082. The 95% confidence interval for sex means ranged from -1.07 to .336. An examination of the mean for cognitive coping for positive male (M = 13.91, SD = 3.9) and the mean for cognitive coping positive female (M = 13.6, SD = 3.6) indicated there are no differences in cognitive coping between the two groups. The two tail independent measures *t* test was conducted to determine if the independent variable sex (positive male and positive female) differ significantly based on the dependent variable emotional coping. The results were not significant, t (138) = 1.189, p = .23, d = 0.196. The 95% confidence interval for the means for sex ranged from -303 to .931. An examination of the means for emotional coping for positive male (M = 13.9, SD = 3.5)

and the mean for emotional coping for positive females (M = 13.16, SD = 4.0) indicated there are no differences in emotional coping between the two groups (see table 4).

Table 4

Means and Standard Deviation and Statistical Information for Sex Results and Cognitive Coping and Emotional Coping

		Male		Female				95%C1		Cohen's
Coping	n	M	(SD)	M	(SD)	*t* (138)	*p.05*	LL	UL	*d*
Cognitive	70	13.91	(3.9)	13.6	(3.6)	.520	.6	[-1.07	- .336]	0.095
Emotional	70	13.9	(3.5)	13.16	(4.0)	1.189	.23	[-303	- .931]	0.200

These findings indicate there were no significant differences in coping strategies between sexes who had positive susceptibility test results for possibly developing AD in the future, 12 months or more after receiving their test results. The null hypothesis is confirmed.

Summary

In this chapter the results of the study were presented. The results for research question one rejected the null hypothesis, there were significant differences in coping strategies between the test result positive (P) group and the negative (N) group as measured by the Brief COPE scale for the dependent variables cognitive coping and emotional coping. Individuals with positive genetic susceptibility test results 12 months

or more after receiving their genetic test results presented significant differences in their use of cognitive and emotional coping strategies.

The results for research question two did not yield significant between sex (males and females) with positive genetic susceptibility test results and dependent variables cognitive coping and emotional coping as measured by the Brief COPE scale. Therefore, the null hypothesis was confirmed.

In Chapter 5 a summary of the interpretation of the statistical findings, the limitations of this study, recommendations for future studies, the implications for social change, and the conclusion were presented.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this quantitative online study was to examine whether differences exist in coping strategies based on testing results between individuals who had received positive or negative genetic susceptibility test results for the APOE-4 gene, beyond the first 12 months following test results. The study also examined coping strategies of the sexes with positive genetic susceptibility test results beyond the first 12 month period. The APOE-4 gene has been associated with possibly developing AD in the future (Lage, 2006). The study was conducted to help fill the gaps in the literature on coping strategies used by individuals who undergo genetic susceptibility testing for the APOE-4 gene, beyond the first 12 month period following testing. This study tested two hypotheses using an independent measures *t* test. The first hypothesis sought to examine if differences in coping strategies exist between test results of a group who received positive genetic susceptibility test results, and a group who received negative genetic susceptibility test results for the APOE-4 gene, 12 months or more after receiving their test results. The second hypothesis sought to examine if differences in coping strategies exist between sexes, who received positive genetic susceptibility test results for the APOE-4 gene, 12 months or more after receiving their test results. Each of these questions addressed areas within the literature where limited research has been conducted.

Current literature reported that coping strategies change based on genetic susceptibility test results (Green, 2007), as measured by the Impact of Genetic Testing for

AD. The IGT-AD developed by Cella et al. (2002) was used in the studies of coping behaviors such as health behavior, dietary behavior and chronic stress, conducted under the REVEAL research project. The current study used the Brief COPE scale. The Brief COPE scale has been used in the study of coping behaviors related to health issues, and chronic stress. The IGT-AD was not available for use for this study. The current view in the literature is that differences exist between sexes in the selection of coping strategies (Chipperfield et al., 2007). Gooding et al., (2006) suggest future research in genetic susceptibility testing for AD include coping strategies between sexes.

The present study was conducted online over a three month period, 280 participants were selected from 312 responses, 70 positive males, 70 positive females, 70 negative males, and 70 negative female participants for a total of 140 males and 140 females. Each of the participants was given a $10.00 Starbucks e-gift certificate for participating.

The data analysis for the independent variables test results (positive and negative groups), sex (males and females), and the dependent variables cognitive and emotional coping strategies were analyzed using a independent measures *t* test. There were significant differences for test results between the positive and negative groups, indicating there are differences in cognitive and emotional coping strategies between the two groups.

The results of the independent measures *t* test for the independent variable of sex (males and females), and the dependent variables cognitive and emotional coping strategies, with positive genetic test results for AD were not significant, indicating there were no

differences in cognitive and emotional coping strategies between the sexes, 12months or more after genetic testing as measured by the Brief COPE scale.

The following paragraphs present a discussion of the results of the analyses: conclusions based on those analyses, recommendations for further studies, and social change.

Interpretation of the Findings

The findings of this study were consistent with the overall body of research studies which have found significant differences in coping strategies following positive and negative genetic susceptibility test results for AD. The significant findings for the positive groups in this study, were consistent with the previous findings of Fanshawe et al. (2008) on health behavior, Hiraki et al. (2009) study on chronic stress, and the Vernarelli et al. (2010) study on dietary behavior. Each of these studies found significant differences in coping behavior between positive and negative groups after genetic susceptibility test results.

The methodology utilized in the REVEAL Research project studies (Fanshawe et al., 2008; Hiraki et al., 2009; & Vernarelli et al., 2010) differed from that of the current study. Participants in the REVEAL studies were provided educational counseling via group and individual sessions, on diet, exercise and medication that may possibly prevent AD. Participants were cautioned that currently there was no way of preventing the disease. Following participation in the educational program, the participants were tested for the APOE-4 genes associated with AD and given their test results. At 6 weeks, 6 and 12 months the participants were asked about their diet, exercise and /or use of vitamin

and medication to prevent AD. Based on the results, it was determined if coping strategies were utilized. The impact of educational intervention and times of inquiry are issues that may have prejudiced the outcome. Regardless, what was not known was if beyond 12 months participants' positive for the APOE-4 genes associated with AD utilized coping strategies. The past studies and the current study all resulted in significant findings indicating that positive genetic susceptibility test results for developing AD in the future, does have an impact on coping strategies during the first 12 months and beyond the 12 months following test results.

The current study found participants who were positive for the APOE-4 gene associated with AD utilized coping strategies beyond the 12 month period following genetic susceptibility testing.

During the literature search no studies were found examining coping strategies between sexes who had received positive genetic susceptibility test results for developing AD in the future. A study was found that was related to coping differences between sexes conducted by Chipperfield et al. (2007). Chipperfield et al. examined coping differences between sexes when faced with health problems. The participants in the study all had either suffered a heart attack or stroke. The researchers examined primary and secondary control coping strategies used by men and women. The Chipperfield et al. study produced findings of significance, for secondary control used by women. Women were found to use secondary control more often than men when faced with health problems.

The current study did not produce findings of significance between the sexes. The lack of studies based on positive genetic susceptibility test results between the sexes

leaves these findings open to interpretation. It is possible the Brief COPE scale questions were too general to elicit more direct responses. The coping behavior of the participants in the current study were not being examined based on either a heart attack or a stroke, but on information received by them of their genetic susceptibility test results for the APOE-4 gene.

Limitations of the Study

There are some limitations to this study. First was the method of data collection; the survey was anonymous no personal data were collected, thereby limiting the my ability to scan for participants who may have taken the survey more than once. Each participant received $10.00 e-gift certificate for participating in the study. I was not able to determine if any participant received more than one certificate as they were automatically downloaded. A second limitation of this study was the results can only be applied to members of this special population who have been tested for the APOE-4 gene associated with the development of AD. This limits the generalizability of this study to other genetically based diseases. Further limitation of the study was that only one measure of coping was used, and it did not gather information on general health.

A further limitation of this study is its inability to be generalized to individuals who had been given positive or negative genetic susceptibility test results for AD, but have no first or second degree relative who have been diagnosed with AD. The APOE-4 gene is specifically genetically associated with first and second degree relatives. A final limitation of this study is the lack of information about the participants' coping strategies before this study, that is, within the first 12 months after receiving genetic susceptibility

test results, and prior to the participants being tested for genetic susceptibility for the APOE-4 gene. The my inability to compare the participants' coping strategies and behavior before genetic susceptibility testing, and within the first 12 months after receiving genetic test results, also limits the data being generalized to the public.

Conclusion

Research studies have in the past been conducted to examine coping behaviors of individuals who have been given positive or negative genetic susceptibility test results for developing AD in the future, within the first 12 months following test results. This study was conducted to add to that body of literature. The current study examined cognitive and emotional coping strategies used by individuals with either positive or negative test results for the APOE-4 gene beyond the first 12 month of receiving test results. The study also included the examination of coping strategies between the sexes with positive genetic susceptibility test results. Studies in the past have focused on diet, dietary supplemental behavior changes, health behavior, and chronic stress, these studies produced findings of significance. The current study did not focused on any specific area of coping rather, it examined general coping behaviors. Past studies have been noted for having a disproportionate number of women in the participant pool. The current study had equal numbers of males and females in each group.

Significant findings were produced by the current study, consistent with past studies. It should be noted that previous studies produced significant findings for the positive group within the first 6 to 12 month period following test results. The current

study produced significant findings for the positive group after the 12 month period following genetic susceptibility test results.

The significant results of the current study fit well with the two theories used for this study; Rothbaum et al. (1982) theory of primary and secondary control, and Lazarus and Folkman (1984) theory of stress, appraisal and coping that has two main components problem focused coping and emotional focused coping. The findings of significant differences in coping between the positive and negative groups may indicate the possible use of primary control, secondary control, problem focused and emotional focused coping. Primary control coping and problem focused coping are used when the individual feel they may have control over the stressor and attempt to relieve the stressor (genetic test results) by taking some form of action. In past studies the action taken was to change diets and the use of dietary supplements. In the current study the actions reported were based on questions such as: "concentrating my efforts on doing something about the situation ", and "I've been taking action to try to make the situation better" (Brief COPE scale questions 2, & 7). Secondary control and emotional focused coping are used when the individual feel they have no control over the stressor and attempt to relieve the stressor (genetic test results), by either accepting or denying the situation. In past studies it was reported that when individuals feel they have no control over his or her health, their perception was affected, there was greater concern, secondary control was employed (Marteau et al. (2005). In the current study acceptance and denial were based on questions such as: "I've been giving up trying to deal with it", and "I've been saying to myself this isn't real" (Brief COPE scale questions 6, & 3).

Implications for Social Change

The results of this study may help to implement positive social change for individuals who have undergone genetic susceptibility test results for the APOE-4 gene, their families, psychologists, mental health counselors, and the general public. Individuals with positive results can review this study and past studies which may help them understand the behavior changes they may be experiencing. Roberts et al. (2011) reported coping changes become an important issue for individuals faced with positive genetic test results. Having access to the current study may help decrease the stress the individual and his or her family might be experiencing by knowing that changes in behavior are common. This study also contributes to social change adding knowledge that can impact decision making by the individual regarding finances, family and work adjustments which may affect their community, society and their general life style.

The current study used two coping theories, Rothbaum et al. (1982) theory of primary and secondary control and Lazarus and Folkman (1984) theory of stress, appraisal and coping which has two components: problem focused coping and emotional focused coping. The individual and his or her family's understanding of these theories and how they may apply to the individuals' behavior may help to promote positive social change. Positive social change may occur by the individual and his or her family developing a better understanding of possible behavioral changes. The use of primary control and problem focused coping as a positive coping strategy is the process of actively doing something to alleviate the stressor (positive test results). Changes in the individuals' behavior in past studies may have been an attempt to change or eliminate the

stressor of positive genetic susceptible test results. The significant findings in the current study maybe the results of the individuals' use of primary control, and problem focused, as a positive coping strategy that enabled the individual to accept circumstances they feel they can control. When the individual uses secondary control and emotional focused coping they believe they cannot control the stressor of positive testing results, and therefore attempt to assimilate or deny the stressor of positive test results. The significant results of this study may also be the result of the individuals' using secondary control and emotional focused coping strategy to allow the individual to minimize the stressor and attempt to relieve the emotional stress of positive genetic susceptibility test results.

The families of the individuals can benefit from this study by developing a better understanding of the effect of genetic susceptibility test result for AD, and the coping behaviors described in the theories reported in the previous paragraph. By understanding the individuals' coping behaviors, the family members will be able to offer emotional support (Chipperfield et al., 2007), thereby, creating an environment of positive social change. Psychologists and mental health counselors, who treat individuals following genetic susceptibility testing, can use the results of this study and others studies to better understand the coping behavior of the individuals they treat. The study may help in the selection of, or rule-out the type of treatment the individual may or may not need. This study may also help psychologists and mental health counselors in the development of treatment plans that adjust overtime to the needs of their clients.

The public's awareness of the information from this study and related studies may result in positive social change. The public will be able to get a better understanding of

possible changes that may occur in an individual based on the genetic susceptibility test results (Roberts et al., 2011; Zonno & Terry, 2009). It has been suggested by researchers (Chipperfield et al., 2007; Gooding et al., 2006; Linnenbringer et al., 2010; Vermicelli et al., 2010; and Zonno & Terry 2009), that a better understanding of genetic susceptibility test results for AD will aid in, and create an environment of positive acceptance of genetic testing within the public domain.

Recommendations

This study was designed to examine coping strategies used by individuals who have been tested for genetic susceptibility for developing AD in the future. Information from this study is to be added to the growing body of literature currently being compiled on genetic susceptibility testing and coping responses. As the number of genetic susceptibility tests becomes available to the general public (Zonno & Terry, 2009), the number of individuals getting genetic susceptibility test increases. The need by psychologists, genetic counselors, and mental health professionals to understand the coping behavior of individuals who have undergone genetic susceptibility testing also increases. It is therefore recommended that further studies be conducted into the coping behavior of individuals who have undergone genetic susceptibility testing for developing AD or other debilitating or fatal disorders based on genetic factors.

The current study produced significant findings between positive and negative groups. The study did not produce significant findings for sex differences in coping strategies between sexes with positive genetic susceptibility test results. However, it has been suggested by several researchers, (Gooding et al., 2006; Linnenbringer et al., 2010;

Vernarelli et al., 2010) that research into the coping strategies between sexes be studied. It is therefore recommended that further research in this area be conducted.

Christensen et al., (2008), Linnenbringer et al., (2010), and Vernarelli et al., (2010) reported that age is a factor in coping changes and that age has been included in previous research. It is recommended that in future studies age be included. It is further recommended that in future studies, specific cognitive and emotional coping strategies be examined. It is recommended that coping behaviors of the participants be examined prior to genetic susceptibility testing, within the first 12 months, and beyond the 12 month period following receiving genetic susceptibility test results. It is possible that length of time beyond the first 12 month period may be a factor in coping with genetic test information. It is also recommended that a different measuring instrument such as the Impact of Genetic Testing for AD (IGT-AD) developed by Cella et al. (2002) be used. The IGT-AD would possibly have been a better instrument to measure coping strategies based on genetic testing, and may have yielded different findings for sexes. At the time of this study the IGT-AD was not available for use other than by researchers who are part of the REVEAL research project. It is hoped that in the future, the IGT-AD will become available to researchers outside of the REVEAL research project.

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Appendix A: ALZ Trial Match

From: Ncvmed

Sent: Monday, December 09, 2013 1:53 PM

To: ALZ Trial Match

Subject: Posting a flyer for participant study

Hello,

My name is Diana E. Neverson, I am a PhD Counseling Psychology student at Walden University. Current, I have IRB approval for my dissertation study. I would like to post a flyer announcing the study on the Alzheimer Association Website. My study is not a clinical trial, it is a study requiring potential participants to answer 28 questions on the Brief COPE Scale.

I would be happy to fill-out your application and to include all documents. At present, I am not sure if my study requires the filling out of your form.

Attached to this email is a letter of request and the flyer announcing the study. Any help you can give me would be greatly appreciated.

Thank You

Diana E. Neverson

Appendix B: Letter of Request

Letter of Request for Community Research Partner Consideration

Date: December 9, 2013

My name is Diana E. Neverson, I am a Psychology Doctoral Candidate at Walden University. Currently, I am writing my dissertation proposal titled; "Coping Responses to Positive Genetic Susceptibility Test Results for Alzheimer Disease." The focus of my study is the coping strategies used by an individual after receiving positive or negative genetic susceptibility test results for possibly developing Alzheimer disease.

I am writing to your association asking for your consideration to allow me to reach-out to your clients to be participants in my study. I would like, with your consent, to place a flyer describing my study on your website and at your site locations (see attachment to email), following Walden University IRB approval of the study. The Flyer states what the study is about, the requirements participants must have to be a part of the study, and how I may be contacted.

If your association should consider possibly being a Research Source Partner, please contact me at the email address listed below. Upon Walden University's IRB approval, I will forward to you a Research Source Partner form to be electronically signed.

Thank You

Diana E. Neverson

Appendix C: Flyer

INDIVIDUALS NEEDED TO PARTICIPATE IN RESEARCH

Individuals 45 years old to 75 years old needed for survey.

If you have undergone genetic susceptibility testing for the APOE-ε4 gene 12 months or more ago, you are eligible to participate in a research study exploring Coping Strategies. Participants will be asked to complete a demographic questionnaire and complete an online survey consisting of 28 questions assessing coping strategies. The survey will be completed in one session and will take approximately 30 to 45 minutes. Participants' personal information will not be used. All information will be kept confidential.

If you would like more information about becoming a participant in this study, please contact the researcher directly at by email at; diana.neverson@waldenu.edu.

All questions and concerns will be addressed before the survey. All participants have a right to withdraw from the study at any time, no questions will be asked. The protection of the participant is the main concern and priority. This study has been reviewed and approved by a dissertation committee and Walden University's Institutional Review Board.

Research Disclaimer:

The results of the survey cannot serve any diagnostic purpose and the researcher cannot provide individual diagnoses or interpretations. By request, you will be provided with a list of clinicians in your area which can provide counseling in the event you would like further evaluation.

ALL INFORMATION WILL BE KEPT CONFIDENTIAL. NO PERSONAL IDENTIFYING INFORMATION WILL BE TAKEN

Appendix D: IRB Approval

IRB Materials Approved-Diana Neverson

1 message

IRB <IRB@waldenu.edu> Wed, Dec 4, 2013 at 3:47 PM

Reply-To: IRB <IRB@waldenu.edu>

To: "diana.neverson@waldenu.edu" <diana.neverson@waldenu.edu>

Cc: Walden University Research <research@waldenu.edu>,

"maureen.levine@waldenu.edu" <maureen.levine@waldenu.edu>

Dear Ms. Neverson,

This email is to notify you that the Institutional Review Board (IRB) has approved your application for the study entitled, "Coping responses to positive genetic susceptibility test results for Alzheimer's disease."

Your approval # is 12-04-13-0114017. You will need to reference this number in your dissertation and in any future funding or publication submissions. Also attached to this e-mail is the IRB approved consent form. Please note, if this is already in an on-line format, you will need to update that consent document to include the IRB approval number and expiration date.

Your IRB approval expires on December 3, 2014. One month before this expiration date, you will be sent a Continuing Review Form, which must be submitted if you wish to collect data beyond the approval expiration date. Your IRB approval is contingent upon your adherence to the exact procedures described in the final version of the IRB application document that has been submitted as of this date. This includes maintaining

with the university. Your IRB approval is only valid while you are an actively enrolled student at Walden University. If you need to take a leave of absence or are otherwise unable to remain actively enrolled, your IRB approval is suspended. Absolutely NO participant recruitment or data collection may occur while a student is not actively enrolled.

If you need to make any changes to your research staff or procedures, you must obtain IRB approval by submitting the IRB Request for Change in Procedures Form. You will receive confirmation with a status update of the request within 1 week of submitting the change request form and are not permitted to implement changes prior to receiving approval. Please note that Walden University does not accept responsibility or liability for research activities conducted without the IRB's approval, and the University will not accept or grant credit for student work that fails to comply with the policies and procedures related to ethical standards in research.

When you submitted your IRB application, you made a commitment to communicate both discrete adverse events and general problems to the IRB within 1 week of their occurrence/realization. Failure to do so may result in invalidation of data, loss of academic credit, and/or loss of legal protections otherwise available to the researcher.

Both the Adverse Event Reporting form and Request for Change in Procedures form can be obtained at the IRB section of the Walden web site or by emailingirb@waldenu.edu: ttp://researchcenter.waldenu.edu/Application-and-General-Materials.htm. Researchers are expected to keep detailed records of their research

activities (i.e., participant log sheets, completed consent forms, etc.) for the same period of time they retain the original data. If, in the future, you require copies of the originally submitted IRB materials, you may request them from Institutional Review Board.

Please note that this letter indicates that the IRB has approved your research. You may not begin the research phase of your dissertation, however, until you have received the Notification of Approval to Conduct Research e-mail. Once you have received this notification by email, you may begin your data collection.

Both students and faculty are invited to provide feedback on this IRB experience at the link below:

http://www.surveymonkey.com/s.aspx?sm=qHBJzkJMUx43pZegKlmdiQ_3d_3d

Alex Dohm

Research Service Specialist

Center for Research Quality

Walden University

100 Washington Avenue South, Suite 900

Minneapolis, MN 55401

Follow us on Twitter for research resources and tips!

Twitter: @WaldenResearchhttps://twitter.com/WaldenResearch

Appendix E: Response from Trial Match

Original Message-----

From: Terri Hewitt <THewitt@emergingmed.com>

To: Ncvmed <ncvmed@aol.com>

Sent: Tue, Jan 14, 2014 4:18 pm

Subject: RE: Posting a flyer for participant study

Hello Diana,

Your study has been approved for posting with TrialMatch. Would you be able to provide the trial summary, eligibility criteria in a document that I can copy and paste from? Since you originally scanned and faxed the documents I'm unable to easily transfer the information.

Thank you,

Terri

Terri Hewitt

EmergingMed

247 W 30th Street, 4th Floor

New York, NY 10001

F: 212 679-1749

www.emerginmed.com

Appendix: F Demographic Information

Demographic Information

1. Date of Survey_____

2. Participant's Age_____

3. Participant's Gender_____

4. Genetic Susceptibility test for Alzheimer's taken 12 months or more prior to entering study;

Yes:_____, No:_____

5. Participant's Susceptibility Test Results; Negative:_____, Positive:_____

Appendix G: Carver Consent Letter

Re: Consent letter to use the Brief COPE scale

Charles S. Carver to you show details

I apologize for this automated reply. All measures I have developed are available for research and teaching applications without charge and without need to request permission; we ask only that you cite their source in any report that results. If you wish to use a measure for a purpose other than that, you must also contact the copyright holder, the publisher of the journal in which the measure was published.

Information concerning the measure you are asking about can be found at the website below. I think most of your questions will be answered there. If questions remain, however, do not hesitate to contact me. Good luck in your work.

http://www.psy.miami.edu/faculty/ccarver/CCscales.html

On Feb 15, 2013, at 1:18 PM, Ncvmed <ncvmed@aol.com> wrote:

Good Afternoon Dr. Carver

My name is Diana E. Neverson, I am a psychology doctoral candidate at Walden University. Currently I am working on my proposal for my dissertation titled:

" Coping Responses to Positive Genetic Susceptibility Test Results for Alzheimer's Disease" I would like to use the Brief COPE scale and need written consent from you. If it is not too much of a problem, would you please email me permission to use the scale? My email addresses are: diana.neverson@waldenu.edu or: Ncvmed@aol.com

I thank you in advance for your help and consent.

Appendix H: Brief COPE Scale Coding

Brief COPE Scale Coding

Scales are computed as follows (with no reversals of coding):

Self-distraction, items 1 and 19

Active coping, items 2 and 7

Denial, items 3 and 8

Substance use, items 4 and 11

Use of emotional support, items 5 and 15

Use of instrumental support, items 10 and 23

Behavioral disengagement, items 6 and 16

Venting, items 9 and 21

Positive reframing, items 12 and 17

Planning, items 14 and 25

Humor, items 18 and 28

Acceptance, items 20 and 24

Religion, items 22 and 27

Self-blame, items 13 and 26