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Effects of Knowledge and Anxiety on Willingness to Screen for Alzheimer's Disease

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**EFFECTS OF KNOWLEDGE AND ANXIETY ON WILLINGNESS TO SCREEN
FOR ALZHEIMER'S DISEASE**

A Thesis Presented

by

TESSA S. LUNDQUIST

Submitted to the Graduate School of the
University of Massachusetts Amherst in partial fulfillment
of the requirements of the degree of

MASTER OF SCIENCE

February 2012

Clinical Psychology

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ABSTRACT

EFFECTS OF KNOWLEDGE AND ANXIETY ON WILLINGNESS TO SCREEN FOR ALZHEIMER'S DISEASE

FEBRUARY 2012

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While the prevalence rates of Alzheimer's disease (AD) are increasing, the screening rates for the disease are low. A major barrier to AD screening is older persons' lack of knowledge about the disease (Ayalon & Arean, 2004). Older adults have anxiety about AD (Corner & Bond, 2004; Devlin et al., 2007), but less is known about how that anxiety may affect their screening behavior. The current study measured AD Knowledge and AD Anxiety and determined how these factors were related to Willingness to Screen for AD in a sample of midlife and older adults ($N = 96$, mean age = 62.45, range 55 to 86). It was expected that greater AD Knowledge would be associated with more Willingness to Screen and that higher AD Anxiety would be associated with less Willingness. Further, it was hypothesized that AD Anxiety would moderate the relationship between AD Knowledge and Willingness. AD Knowledge and Trait Anxiety were not significant predictors of Willingness to Screen, while AD Anxiety was positively associated with Willingness. AD Anxiety moderated the relationship between AD Knowledge and Willingness. When individuals had lower AD Anxiety, their Willingness increased as their AD Knowledge increased. In contrast, for participants with relatively more AD Anxiety, their Willingness decreased as their AD Knowledge

increased. Understanding how knowledge about AD affects older adult screening preferences differently based on the amount of anxiety they have about AD will facilitate development of the most effective interventions to increase awareness about AD and promote screening.

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CHAPTER I
THE CURRENT STATE OF ALZHEIMER'S DISEASE AND SCREENING
STANDARDS

The United States population is aging at an unprecedented rate and chronic diseases related to aging are affecting more individuals and families. Alzheimer's disease (AD) is one of the most prevalent diseases of aging; an estimated 4.5 million Americans are currently diagnosed with AD and an estimated 7.7 million are expected to have the condition by 2030 (Burgener & Berger, 2008). AD causes suffering for families as well as societal burden, with an annual estimated cost close to 100 billion dollars (Boustani et al., 2005; Ernst, Hay, Fenn, Tinklenberg, & Yesavage, 1997). AD is generally met with misunderstanding, fear, and stigma (Devlin, MacAskill, & Stead, 2007).

Despite five FDA approved drugs for AD that can temporarily slow the progression of symptoms (Alzheimer's Association, 2008), and the fact that active management of the disease can improve quality of life for patients and their caregivers (Connell, Roberts, McLaughlin, & Carpenter, 2009), older adults are reluctant to seek screening for AD. One major reason that older adults are not screened is a lack of knowledge about AD and its symptoms (Ayalon & Arean, 2004). Older adults do not know when or why it is necessary to seek memory evaluations (eg., Devlin et al., 2007; Galvin, Fu, Nguyen, Glasheen, & Scharff, 2008; Knopman, Donohue, & Gutterman, 2000; VonDras, 2009; Hughes, Tyler, Danner, & Carter, 2009; Werner, 2003b). Thus, many researchers have suggested implementing programs to raise awareness about AD and encourage screening by increasing knowledge about the disease and its available treatments.

Another barrier to screening may be anxiety about AD, but less is known about the effect of anxiety on screening behavior. Whereas dementia clearly evokes anxiety and feelings of dread in older adults (Corner & Bond, 2004; Devlin et al., 2007), the extent to which those feelings of anxiety may prevent older adults from screening, especially if they are experiencing memory problems, is not known. The current study will address this gap in the literature by measuring older adults' anxiety about AD and how it is related to willingness to screen. In addition, older adults' knowledge about AD and how it is related to willingness to screen will be measured. Further, the current study will examine how anxiety and knowledge may work together in predicting older individuals' willingness to screen. It is important to investigate not only how knowledge impacts willingness to screen, but also how anxiety about AD may affect older persons' screening behaviors. By understanding the impact of knowledge and anxiety on individuals' willingness to screen for the disease, effective interventions aimed at encouraging screening can be implemented.

CHAPTER II

KNOWLEDGE ABOUT ALZHEIMER'S DISEASE

A. Deficits in Knowledge about Alzheimer's Disease

As stated above, knowledge about AD affects older individuals' willingness to screen for the disease. In a study exploring how certain psychosocial factors are related to willingness to screen for AD, Galvin et al. (2007) found that knowledge of AD and its consequences was a significant predictor of willingness to screen. Participants who had knowledge about dementia and had some idea of the negative impact AD could have on them and their family members were most likely to express intention to screen for AD. Similarly, in a study measuring the relationship between knowledge about AD and willingness to seek help for the disease, Werner (2003b) found that older individuals having a higher amount of knowledge about AD symptoms were significantly more likely to express intention to seek professional help for memory problems. However, older adults often show wide-ranging deficits in knowledge about AD, including poor knowledge about symptoms, available treatments, course and severity of the disease, and etiology of AD (Ayalon & Arean, 2004). Older individuals cite deficits in knowledge as obstacles to seeking assessment for AD. For example, many persons think that all memory problems are parts of normal aging, that a diagnosis of AD is unnecessary, and that there is no treatment for AD (Connell et al., 2009). In a study of in-depth interviews with older persons, Werner (2004) found that older individuals generally thought that memory problems were an inevitable part of aging. Participants who had knowledge

deficits about normal aging versus AD symptoms expressed more reluctance about seeking AD screening.

B. Identifying Memory Changes

Often, older persons are not able to distinguish memory changes due to normal aging from those that are early signs of AD (Werner, 2004; Knopman et al., 2000). Memory normally declines with age, with younger persons performing better on memory tasks and having fewer memory impairments than older persons (Cutler & Hodgson, 1996). Devlin et al. (2007) conducted qualitative interviews with persons over the age of 50, who will be at a higher risk for AD as they age. They wanted to explore the views that adults had about AD to get an idea about how mass media campaigns designed to raise awareness about dementia could be most effective in the future. Focus groups were conducted with older persons to explore issues such as knowledge and awareness about AD, perceptions and beliefs about treatment and support for AD, and issues related to approaching a primary care doctor with concerns about AD (Devlin et al., 2007). Results indicated that even though participants had a general awareness about dementia, they had significant misperceptions about AD. Participants were uncertain about the onset of the disease and what memory changes were normal for aging, including what memory problems would be considered severe enough to be symptomatic of AD (Devlin et al., 2007). One participant said “I forget quite a lot, I don't think it's got anything to do with dementia” (Devlin et al., 2007, p. 51). The respondents' uncertainty about the onset of AD may have led to some complacency about memory problems. Several participants reported that when they experienced memory changes, they would attribute them to normal aging, until

the symptoms became so bad that they could not avoid them any longer (Devlin et al., 2007).

A common memory occurrence that would be considered normal for aging would be forgetting names or appointments, but then being able to remember them later. This type of memory change is called a retrieval deficit, which means that information that is stored in memory is not easily accessible (Broder, Herwig, Teipal, & Fast, 2008). Most older persons would be able to retrieve the memory eventually, while someone with AD would not. Memory impairment in AD is partly attributed to difficulty with storage and retrieval of long-term memories, as well as deficits in learning new material (Chang et al., 2010). Though some types of memory problems are considered normal for aging and are common in daily life (i.e., retrieval deficits), they are different from memory loss (i.e., amnesia) that is symptomatic of AD. Cognitive impairment, a symptom of AD, occurs when deficits contribute to functional impairment that is sufficient to interfere with everyday activities (APA, 2000). An example of a functional change associated with aging would be an individual occasionally needing help adjusting the television or operating appliances, whereas a sign of AD would be an individual having difficulty completing daily tasks, such as having difficulty driving to familiar places, or being unable to manage work duties (Alzheimer's Association, 2008). In AD, functional impairment is often accompanied by changes in mood, personality, and behavior (Rabin et al., 2008).

C. Knowledge about Treatment Options

In addition to not being able to identify symptoms of AD, many older individuals also do not have knowledge about available treatments for AD. To measure what older

individuals thought were barriers and benefits to seeking a diagnosis of AD, Connell et al. (2009) administered questionnaires to a sample of adults. All respondents reported having a family member currently diagnosed with AD. Connell et al. (2009) found that many participants endorsed screening barriers that were related to treatment, such as items stating that “so little can be done for people with AD” and “there is no effective treatment for AD” (Connell et al., 2009, p. 1565).

Werner (2003a) examined barriers associated with older adults’ intention to seek memory screening when those older adults felt that they were experiencing memory problems themselves. Barriers included a lack of knowledge about the utility of having a memory evaluation and a lack of knowledge about treatments for the disease (Werner, 2003a). As discussed previously, Devlin et al. (2007) found that the majority of older individuals in their sample were unsure of how to distinguish normal memory changes related to aging from memory symptoms of AD. They also found that participants were not aware of drug treatments and did not believe that there was any clinical treatment available for AD, which contributed to participants’ perceptions that there was little benefit to seeking diagnosis (Devlin et al., 2007). When exploring older adults’ intention to seek memory screening in the presence of memory problems through in-depth interviews, Werner (2004) found that individuals who believed in the efficacy of AD treatment expressed a greater intention to seek help for memory problems.

D. Knowledge about Risks and Consequences

When older adults lack knowledge about AD it can affect how susceptible they think they are to developing the disease, which in turn can affect their willingness to

screen for it. Galvin et al. (2007) measured intention to screen for AD in a sample of older adults and found that in addition to having knowledge about the disease in general, older adults who were able to recognize the consequences of having AD and its negative effect on them and their family were most likely to express intention to screen (Galvin et al., 2007). These individuals were able to see a tangible benefit to seeking a diagnosis for AD through their knowledge about the disease, which outweighed what they thought were barriers to screening. Perceived susceptibility is greatly affected by knowledge of the disease in general, as well as the specific knowledge that AD is an illness and not a part of normal aging (Hughes et al., 2009). Galvin et al. (2007) suggest that more knowledge about AD leads to more perceived susceptibility and higher perceived benefit to screening, noting that increasing knowledge in older adults would have a positive impact on screening behavior.

E. Ethnic Differences in Knowledge

Differences in ethnicity serve as an example of the importance of knowledge in individuals' willingness to screen for AD. Ayalon and Arean (2004) found that there were significant differences in amount of knowledge about AD across four different ethnic groups of older adults. Even though AD is more prevalent in certain ethnic groups, with rates being highest in African Americans, these groups are likely to receive diagnoses of AD at later stages in the disease, which in turn limits their access to early interventions and available treatments (Ayalon & Arean, 2004; Hughes et al., 2009). Ayalon and Arean (2004) tested Anglo-Americans, Latino, Asian, and African American older adults and found that across all groups, the majority of older persons had significant misperceptions about AD in general, including prevalence, etiology, diagnosis, financial options for

treatment, and course of the disease. African Americans, Latino, and Asians had significantly less knowledge about AD than Anglo Americans. Additionally, some ethnicities held inaccurate beliefs about the etiology of AD. Ayalon and Arean (2004) found that Asian American and Latino older individuals thought of AD as a contagious disease and tended to think of memory problems as being caused by the fault of the individual. Certain ethnic groups' lack of knowledge about AD could account for their low detection rates (Ayalon & Arean, 2004). The authors suggest that interventions and campaigns to increase awareness in minority populations should try to increase knowledge about AD and inform, for example, that it is not contagious and is not a normal part of aging (Ayalon & Arean, 2004).

Hughes et al. (2009) found a lack of knowledge about AD in ethnic minority caregivers of individuals diagnosed with AD. They retrospectively studied experiences of African Americans and what led them to seek an AD evaluation for their family member by conducting interviews with caregivers of persons with AD, which included mostly adult children of AD patients, and a small number of spouses. When asked "Prior to your family member being diagnosed, how much did you know about Alzheimer's disease?" most caregivers reported having little knowledge of the disease (Hughes et al., 2009). One participant said "I first learned about it when I discovered that my mother was diagnosed with the illness. I really did not know about it, I mean I had heard the word, the term, but I never did understand it that well until it happened to my mom" (Hughes et al., 2009, p. 103). Multiple caregivers noted that they were aware of AD as a disease prior to the diagnosis of their family member, but lacked sufficient knowledge of symptoms, progression of the disease, and behavioral changes associated with AD (Hughes et al.,

2009). In fact, almost half of the respondents initially attributed the memory impairment, loss of intellectual ability, and personality change seen in their family member to normal aging. Research has shown that African Americans generally have less knowledge about AD (Ayalon & Arean, 2004) which contributes to the fragmented process and delay to diagnosis that they often experience (Hughes et al., 2009).

CHAPTER III

ANXIETY ABOUT ALZHEIMER'S DISEASE

A. Research Exploring Anxiety about AD

As reviewed previously, the amount of knowledge a person has about the symptoms of AD, the impact of the disease, available treatment options, and the usefulness of screening are related to individuals' willingness to screen for AD, but the *feelings* an individual has about the disease may play a crucial role as well (Corner & Bond, 2004). Knowledge about AD may not be enough to explain screening behavior. Minimal research has examined how individuals decide whether and when to seek memory evaluation once they have identified memory impairment in themselves (Connell et al., 2009). It is clear that aging may be anxiety provoking for some individuals, demonstrated, for example, by a reluctance to interact with older persons or refusal to acknowledge one's age (Lasher & Faulkender, 1993). AD also evokes anxiety and feelings of dread in older adults and is associated with fears of losing control, identity, and dignity (Devlin et al., 2007). When measuring general health anxiety of community-dwelling older adults, Wisocki et al. (1988) found that failing memory was one of their primary health related worries (as cited in Borgault-Fagnoult & Hadjistavropoulos, 2008).

To begin to look at feelings about AD, Corner and Bond (2004) conducted qualitative interviews with older adults. The sample included adults over the age of 60 taken from a larger study examining quality of life from the perspective of individuals diagnosed with dementia and their caregivers. Overall, participants had considerable fear

and anxiety about developing AD. While there were individuals who could identify memory problems as possible AD symptoms, some of them reported that anxiety would inhibit them from seeking a memory evaluation (Corner & Bond, 2004). One participant was quoted as saying “As soon as you get forgetful you think: 'is it going to happen to me?' It’s frightening really” (Corner & Bond, 2004, p. 147). Another participant said “the mere thought of dementia terrifies me...more than any other thing [disease] to die from...” (Corner & Bond, 2004, p. 148). In fact, the researchers discussed difficulties they had recruiting for the study, when ten of the twenty-five people initially approached declined to participate, citing that they would be uncomfortable discussing the topic of AD and that it would raise painful issues for them. This refusal rate is higher than common for similar studies, which may itself serve as an example of the fear and anxiety older individuals have about AD (Corner & Bond, 2004).

B. Stigma and Anxiety

In a study testing the implementation of a screening program for AD, Boustani et al. (2005) sampled patients, ages 65 and older, from seven primary care clinics and offered them a brief six item screening questionnaire of memory functioning. The researchers then offered a full diagnostic evaluation to patients who screened positive for memory impairment. The offer of further evaluation was made with several incentives; the patient's physician recommended it, the study staff talked about the importance of the assessment, and it was offered free of charge, since it was being performed in the primary care clinic. While only six percent of patients refused the brief six-item screening questionnaire, half of the patients with positive screening results refused further diagnostic assessment. This high refusal rate is similar to another study by the same

authors examining attitudes in residents of continuous care communities towards AD screening. In this study, 51% of residents would not agree to routine memory screening (Boustani et al., 2005). The authors note that the high refusal rate in both studies may be related to a fear that a diagnosis of AD would be a source of stigma and could lead to emotional harm (Boustani et al., 2005). In fact, Burgener and Berger (2008) write about a woman who removed her husband from treatment centers for AD and stopped medications for AD because the “diagnosis of Alzheimer’s was just too stigmatizing for her and her husband to accept” (Burgener & Berger, 2008, p.36). Stigmatizing attitudes, which are associated with many chronic diseases, especially those involving mental health, can make persons more anxious about developing the disease themselves (Jorm, 2000). When designing a campaign to increase awareness about AD, Devlin et al. (2007) found that the public generally held negative views towards individuals with dementia, because they tended to think about persons with AD in the later and more severe stages of the disease.

C. Media Influences

Individuals may form negative attitudes about aging and AD through general public opinion or media images. Many individuals rely on media as their main source of information about chronic diseases and mental disorders. A German study found that the negative depictions of mental diseases in the media led to an increase in negative attitudes about those disorders (Jorm, 2000). In the case of AD, it is usually the most despairing features of the disease that are depicted in the media, contributing to stereotypes about AD and adding to the fear of the disease (Corner & Bond, 2004). Public figures diagnosed with AD, such as former president Ronald Reagan, are

presented as experiencing the most debilitating and dreadful aspects of AD. When conducting in-depth interviews with older individuals to explore their fears about AD, Corner and Bond (2004) found that many participants were influenced by these negative media portrayals when thinking about AD. Participants referenced the media images, focusing on their perceived loss of independence, control, and dignity when expressing their fear about developing AD.

D. How Anxiety May Effect Screening for AD

1. Avoiding Exposure to AD

While it is clear that some older individuals have significant anxiety about developing AD (Corner & Bond, 2004; Devlin et al., 2007; Boustani et al., 2005; Burgener & Berger, 2005), less research has been done on how this anxiety about AD may affect their willingness to screen for the disease. For some individuals, anxiety about a disease will be manifested by their avoidance of that disease. As discussed previously, Corner and Bond (2004) conducted interviews with older adults and found that they had considerable fear and anxiety about AD. They found that many participants actively tried to distance themselves from the possibility of having AD. Particularly, participants who had a family history of the disease purposely did not tell their primary care doctors about memory loss they were experiencing, reporting that they did not want their doctor to realize the family connection and evaluate their memory further (Corner & Bond, 2004). Participants wanted to put off the inevitable as long as possible, and were frightened of hearing from their doctors that they might have AD. Corner and Bond (2004) also found that negative feelings about AD came from the experiences of visiting friends and family members with the disease who were living in a long term care setting.

These individuals formed negative views of AD from these visits, which eventually lead them to no longer visit those friends or relatives. Some participants reported consciously trying not to think about AD, with one participant saying “No, I daren’t let myself think about it. I just push it to the back of my mind, and try not to think of it” (Corner & Bond, 2004, p. 148). Individuals who avoid receiving or thinking about threatening disease information report lower levels of anxiety about that disease (VonDras, 2009). Avoiding someone with the disease or avoiding thinking about the disease lowers its perceived threat, and when illnesses are perceived as less life threatening, there may be greater delay in seeking care (VonDras, 2009). In the case of AD, after conducting small focus groups and interviews with adults over the age of 50, Devlin et al. (2007) found that these individuals’ anxieties about AD contributed to a feeling of avoidance of the disease, demonstrated by the participants reporting that they would put off memory evaluation if they were experiencing memory changes. Participants cited feeling frightened of what would happen to them once they received a diagnosis of AD, further reporting feeling shock and dismay at the thought of receiving an AD diagnosis (Devlin et al., 2007).

2. Anxiety Leading to Hyper-vigilance

As discussed above, anxiety may lead to fear and avoidance of AD, which may lead to less willingness to screen and undergo a memory evaluation. Alternatively, anxiety may lead to hyper-vigilant symptom checking, to the point where an individual “symptom-seeks” for memory impairment in themselves (Hodgson & Cutler, 2003; Cutler & Hodgson, 1996). Individuals who are overly anxious about the possibility of developing AD may represent a group of older persons who are the “worried well” (Hodgson & Cutler, 2003). This “anticipatory dementia” involves searching for memory

changes in oneself and identifying them as warning signals of AD. Werner (2003a) found that older adults who worried more about developing AD gave themselves worse memory evaluations than older adults less worried about AD. Suhr and Kinkela (2007) studied the process by which believing in negative aging stereotypes contributes to heightened health anxiety about aging. Memory loss is a widespread stereotype associated with aging. Older individuals internalize the stereotype and thus become more sensitive to memory changes in themselves, making them more likely to over-estimate the severity of memory changes that they experience. While the concept of anticipatory dementia is linked to more concern about the disease and increased symptom seeking for signs of AD, research has not examined whether that concern leads to more or less willingness to screen, or other psychological consequences, such as depression in later life (Cutler & Hodgson, 1996). Instead of avoiding screening, these individuals may seek evaluation and treatment when they have no cause to, which increases risks of misdiagnosis and initiation of unnecessary medications (Suhr & Kinkela, 2007).

3. An Ideal Level of Anxiety

When designing an effective campaign to raise awareness about AD, Devlin et al. (2007) found that older persons' anxiety about the disease did contribute to a feeling of avoidance of the disease and the desire to put off receiving a diagnosis of AD. They speculate that providing more information about treatment options and more information about effective social supports, such as education and counseling, could encourage people to seek diagnosis earlier (Devlin et al., 2007). There is a large body of research on health campaigns designed to raise awareness for various diseases. The idea of "fear appeals" is that fear and anxiety about a disease can be utilized by the campaign to motivate persons

to engage in disease prevention behavior (Tanner, Hunt, & Eppright, 1991). In the case of AD, fear appeals may motivate older individuals to approach their doctors and to get screened if they are experiencing memory problems. If older individuals do have anxiety about AD that is affecting their health seeking behavior, anxiety will be important to consider when awareness campaigns are implemented in the future (Devlin et al., 2007).

CHAPTER IV

KNOWLEDGE, ANXIETY, AND WILLINGNESS TO SCREEN FOR AD

A. Current Study

While it is important to understand how knowledge and anxiety may separately affect older individuals' willingness to screen for AD, it is also important to consider how knowledge and anxiety may *interact* in predicting willingness to screen. There are lags between the first signs of AD and when individuals recognize those signs as problems, and also between the first recognition of AD symptoms and professional evaluation (Knopman et al., 2000). Studies have found that only 26% of older persons who worried about their memory functioning consulted their physicians about memory problems (Werner, 2003). These studies indicate that even if an individual is able to identify memory impairment (e.g. they have adequate knowledge about AD), something is inhibiting them from getting evaluated. Anxiety may be one factor that keeps older adults from seeking an evaluation even when they have recognized the symptoms (Corner & Bond, 2004; Von Dras, 2009).

The current study measured knowledge about AD and determined how it was related to willingness to screen for AD in a sample of older adults, aged 55 and older. Anxiety about AD and how anxiety was related to willingness to screen for AD was also determined. Additionally, the interaction between knowledge and anxiety was measured to examine how anxiety may have moderated the relationship between knowledge and willingness to screen.

B. Hypotheses

Based on previous research (Ayalon & Arian, 2004; Werner, 2003; Galvin et al., 2008; Connell et al., 2009), it was hypothesized that less knowledge about AD, as measured by the Alzheimer's Disease Knowledge Scale, would be related to less willingness to screen for AD. The relationship between anxiety and willingness to screen was determined as well. While there are mixed results about anxiety about AD and health-seeking behavior, there are particularly compelling studies that find that anxiety about AD is related to avoidance of the disease (Corner & Bond, 2004; VonDras, 2009; Devlin et al., 2008). Since anxiety about a disease may lead to avoidance of that disease, it was hypothesized that a higher amount of anxiety would be related to less willingness to screen for AD. Additionally, as an exploratory hypothesis, it was expected that anxiety would moderate the relationship between knowledge and willingness to screen. As discussed, there are delays between first recognition of symptoms of AD and eventual memory evaluation (Knopman et al., 2003; Werner, 2003). Even though individuals may have knowledge with which they recognize disease symptoms, they delay in having them evaluated. Anxiety about AD may be one factor that can explain why adults do not seek AD screening. Even if someone has enough knowledge about AD to recognize the symptoms and consequences of the disease, if they have a high amount of anxiety, it may weaken the positive association between knowledge and willingness to screen. While higher knowledge about AD is related to more willingness to screen (Galvin et al., 2007; Werner, 2003b), anxiety about AD may explain why screening rates continue to be low.

C. Significance and Impact

As prevalence rates of AD rise, early detection of AD is becoming more important to introduce treatment in the beginning stages of the disease. It also affords family

members an opportunity to understand their loved one's behavior and make informed decisions about future care (Connell et al., 2009). When individuals receive a diagnosis of AD in the early stages, they can opt to begin treatment programs or even participate in clinical trials where they may be administered experimental treatments not yet available to the public that can be effective in slowing the progression of AD. Interventions such as educational materials and workshops about AD increase a sense of control and decrease distress in caregivers, while drug treatments for AD have been shown to slow the progression of cognitive decline (Ayalon & Arean, 2004; Connell et al., 2009).

The benefits of early detection and diagnosis of AD have driven an interest in screening programs for older persons (Ashford et al., 2007; Werner, 2004). Since it is difficult for patients and primary care doctors to recognize AD, especially when the symptoms are mild, it is important to have effective routine screening tools that can be implemented in primary care settings (Ashford et al., 2007). For older adults who do not have adequate knowledge of AD and its symptoms, it is often not until a triggering event of memory loss occurs, such as forgetting to turn off the stove, that they will seek a memory evaluation (Hughes et al., 2009). Behavior changes and functional impairment associated with AD that remain unrecognized can become dangerous, and safety concerns can arise. For example, individuals with AD have twice the rate of motor vehicle accidents than matched individuals without AD (Knopman et al., 2000).

Once knowledge and anxiety about AD are measured and better understood, the best interventions to promote screening and early detection of AD can be designed. There is extensive knowledge about effective health campaigns which indicate that it is optimal to balance "fear-appeals" as motivation while not causing too much heightened anxiety

about the disease in question (Devlin et al., 2007; Tanner et al., 1991). The amount of anxiety older persons have about AD will affect how they respond to campaigns trying to motivate individuals to screen for AD. By measuring two potential barriers to AD screening (e.g. low knowledge and high anxiety about AD), we will begin to discern whether one acts as a bigger barrier to AD screening and how they may interact, and therefore be able to inform the content of future effective interventions and education campaigns about AD.

CHAPTER V

METHOD

A. Participants

Participants were 111 community-dwelling, English-speaking healthy older adults who were aged 55 years and above. Data from fourteen participants were cut from final analyses because the participants did not provide their age and thus may not have fit one of the main study criteria of being at least aged 55. One participant's data was excluded because she reported having a diagnosis of MCI. The final sample size was 96. Data collection began in July, 2010, and continued until May, 2011. Recruitment involved fliers posted throughout the community with information about the study and tear-offs containing contact information of the investigator and web address of the website where potential participants could complete the survey online. Emails were sent to members of an existing database of older adults. Finally, emails were sent to family members and acquaintances, asking them to pass along information about the study to anyone they knew that fit study criteria and that might be willing to participate. As an incentive, participants were entered into a raffle with the opportunity to win one of four gift cards to a popular book store chain.

B. Procedure

Data were collected mainly through an online survey site. One hundred and seven participants completed the survey electronically via the website. Four participants completed paper surveys in person after attending a local memory event.

The online survey contained an electronic consent form that participants were

required to read and sign before participating. If online participants did not complete the consent page, they could not proceed to the questionnaires and were instead directed to a web page thanking them for their interest and concluding their participation. If online participants did complete the consent page, they were directed page by page to the following questionnaires: Brief Screening Question; Demographic Questionnaire; Willingness to Screen for Chronic Diseases; AD Knowledge Quiz; AD Anxiety Questionnaire; State Trait Anxiety Y2; Ten Item Personality Inventory; Willingness to Screen for AD Questionnaire. Participants who completed the paper version of the survey were given a packet of survey materials to complete in person. The first questionnaire in the survey contained two screening questions asking participants if they currently had a diagnosis of Mild Cognitive Impairment, Alzheimer's disease, or any other type of dementia. If participants did have a diagnosis of AD, MCI, or dementia, their data were not included in analyses. There was an information page preceding the questionnaires with information about what types of questions would be asked and a statement informing participants that they could feel free to skip any items that they did not want to answer. The AD Knowledge quiz and AD Anxiety questionnaire were counterbalanced among surveys, so approximately half of the participants filled out the AD Anxiety questionnaire before they completed the AD Knowledge quiz, and approximately half of the participants completed the AD Knowledge quiz before filling out the AD Anxiety questionnaire. The survey was ordered in this way to detect potential priming effects that could occur from answering quiz questions about AD before filling out the AD Anxiety questionnaire. After completing the survey, participants were provided a debriefing form, as well as an information sheet about AD. All procedures were reviewed and approved by

the Institutional Review Board at the University of Massachusetts Amherst.

A power analysis of the association between the interaction of AD Knowledge, AD Anxiety, and Willingness to Screen for AD was conducted to detect an effect size of .10 of the multiple regression R-squared increase for the moderation effect. Power was run based on Cohen's effect sizes with an alpha set at .05. Power analysis revealed a necessary sample size of 100 subjects. This sample would allow a detection of a small effect size for the interaction of AD Anxiety and AD Knowledge on Willingness to Screen for AD with a power of 80 percent.

C. Measures

1. Brief Screening Questionnaire

The screening questionnaire consisted of two questions asking participants if they currently had a diagnosis of Mild Cognitive Impairment, Alzheimer's disease, or any other type of dementia. The questionnaire contained instructions that if the participant answered yes to either question, they should not fill out any more questionnaires and that their participation would be considered complete. By including this screening questionnaire, any participants who did not fit study criteria were identified and could be excluded from data analysis.

2. Demographic Questionnaire

The demographic questionnaire assessed participants' age, gender, race, occupation, education, marital status, experience with AD, current and/or past psychological and/or neurological diagnoses, and memory concerns. The questionnaire also contained questions about the participant's current health seeking behavior, for example, whether or not they got regular check-ups with their primary care doctor.

3. Willingness to Screen for Chronic Diseases

Willingness to screen for chronic diseases that are common for aging, including AD, was asked at the beginning of the survey, in order to reveal possible differences between how willing participants are to screen for AD versus other diseases of aging. Another purpose of this questionnaire was to lead participants away from assuming that we were mainly interested in willingness to screen for AD. The questionnaire asked participants to rate on a scale of one to ten, with one being “not at all willing” and ten being “extremely willing,” how willing they would be to screen for nine common chronic diseases, such as cancer, heart disease, and AD.

4. AD Knowledge Quiz

Knowledge about AD was assessed using the Alzheimer’s Disease Knowledge Scale (Carpenter, Balsis, Otilingram, Hanson, & Gatz, 2009). It is a thirty item true/false quiz about risk factors, assessment and diagnosis, symptoms, course, life impact, caregiving, and treatment and management of AD. The test can be used to assess knowledge about AD among laypeople, patients, caregivers, and professionals, with higher scores indicating more knowledge about AD. There are no subscales; rather a total knowledge score is derived from this measure. In a sample of 40 adults aged 22-87, scores on the ADKS ranged from 19 to 30 ($M = 24.2$, $SD = 2.4$), there was adequate test-retest reliability of 0.81, and there was adequate internal consistency reliability (Cronbach's alpha = 0.71) (Carpenter et al., 2009).

5. Anxiety Questionnaires

Trait anxiety and AD anxiety were measured. To our knowledge, no questionnaire currently exists that measures an individual’s amount of anxiety about AD. By including

measures of trait anxiety as well as having a measure of anxiety about AD, we could learn if established measures may adequately capture this construct, or if a more specific measure was needed.

6. AD Anxiety

Items to assess anxiety about AD were constructed for this study. Questions were asked on a 5-point Likert-type scale, with participants being asked to rate the extent to which they agree or disagree with each item. In addition to items rated on a scale, there were two open ended questions asking participants to describe their feelings of anxiety about developing AD in the future. By including two open-ended items, we were able to collect potentially interesting descriptive and narrative data on participants' feelings of AD anxiety.

7. State Trait Anxiety Inventory Form-Y2 (STAI)

The trait version of the State-Trait Anxiety Inventory Form Y-2 is a widely used tool to assess clinical anxiety and consists of twenty statements to evaluate how the participant *generally* feels. Test-retest reliability in a sample of 25 college students after 104 days was 0.73. The median internal consistency alpha coefficient was 0.90 (Spielberger, 1983).

8. Ten-Item Personality Inventory (TIPI)

The Ten-Item Personality Inventory is a brief measure of the Big-Five personality dimensions (Gosling et al., 2003). The Big-Five personality framework is a widely used model of personality traits. The TIPI was developed to be a brief screening measure of the Big Five. The TIPI was used in the current study in order to measure Neuroticism as part of the study's measure of trait anxiety. The TIPI was significantly correlated with the

BFI, ranging from 0.65 to 0.87 across the personality domains of Extraversion, Agreeableness, Conscientiousness, Emotional Stability, and Openness to Experience. Test-retest reliability of the TIPI in a sample of 180 college students after six weeks was 0.72 (Gosling et al., 2003).

9. Willingness to Screen for AD

Participants' willingness to screen for AD was asked through a variety of questions. Participants were asked to answer how much they agree or disagree with six statements on a 5-point Likert-type scale. One item asked participants to rate how willing they would be to screen for AD if they felt they were experiencing memory problems. The theory of reasoned action (TRA) indicates that intention is an important predictor of future behavior (Galvin et al., 2007). Asking older individuals if they would be willing to undergo AD screening in the presence of memory problems can indicate their likelihood of future screening behavior. There also was one item asking participants to rate on a scale from one to ten how willing they would be to undergo a screening test for AD if they felt they were experiencing memory problems. This latter item was similar to a study conducted by Werner (2003a), where willingness to screen was measured by one item asking participants to rate how willing they would be to seek a cognitive status examination in the next year on a scale of one to ten. By including this item as well as six others, we constructed a scale measuring willingness to screen for AD. Additionally, the measure included one item asking participants to rate on a scale of one to ten how likely they feel it is that they will develop AD at some point in the future.

CHAPTER VI

RESULTS

A. Preliminary Analyses

1. Participant Characteristics

Data from a total of 96 participants were included in analyses, but there were some missing data due to participants' missing items on individual scales. Scale scores were included in analyses when 20% or fewer items were missing. If participants had more than 20% of items missing on a given scale, their data were excluded from analyses using listwise deletion. In the primary analyses, which included regressions to explore the relationships among AD Knowledge, AD Anxiety, and Willingness to Screen for AD, 81 participants' data were included. In the regression exploring the relationships among AD Knowledge, Trait Anxiety, and Willingness to Screen for AD, 85 participants' data were included in analyses.

Participants averaged 62.45 years of age with 16 years of education (Table 1). The majority of participants reported their race as Caucasian ($n = 94$), one participant reported their race as Hispanic or Latino, and one participant did not provide their race. Because of the lack of racial diversity within the sample, no analyses examined differences in outcomes between races. There were more female ($n = 79$) than male ($n = 17$) participants in the current study. Gender differences for Trait Anxiety, AD Knowledge, Willingness, and AD Anxiety are presented in Table 2. There were no significant differences between genders among these variables.

2. Development of AD Anxiety Score

A Principal Components Factor Analysis was conducted on items from the AD Anxiety questionnaire. On an exploratory basis, two factors were extracted. The factor matrix revealed that six of the fifteen total items loaded highly (>0.50) on one factor. Items loading on the first factor were interpretable and had content related to worry about AD. Items on the second factor had low loadings and content did not converge on a coherent construct. As a result, a second Principal Components Factor Analysis was conducted from which one factor was extracted, which accounted for 29.82% of the total variance. When one factor was extracted, seven items loaded highly (>0.50) on the factor (Table 3). This factor was labeled 'AD Anxiety.' The remaining eight items did not hang together and were excluded from further analyses.

3. Inter-correlations among Anxiety Measures

Correlations were calculated among the three anxiety measures of AD Anxiety, STAI, and Neuroticism. All of these measures were significantly inter-correlated (AD Anxiety and Neuroticism, $r = 0.29, p < .01$; AD Anxiety and STAI, $r = 0.33, p < .01$; STAI and Neuroticism, $r = 0.55, p < .01$). Since the two measures of trait anxiety, STAI and Neuroticism, were highly correlated with each other and assess the same construct, STAI and Neuroticism were standardized and averaged to create a 'Trait Anxiety' variable. AD Anxiety was kept separate and primary analyses were run on both anxiety measures to detect possible differences between trait anxiety and more specific anxiety about AD on willingness to screen for AD.

4. Development of Willingness to Screen for AD Scale

A Principal Components Factor Analysis was conducted on items from the Willingness to Screen for AD questionnaire. One factor was extracted since all of the

items were designed to measure the unitary construct of willingness to screen. Five of the eight total items loaded highly ($>.50$) on one factor, which accounted for 52.76% of the total variance (Table 4). Three items did not load highly on the factor, and thus were excluded from primary analyses. The AD item on the Willingness to Screen for Chronic Diseases questionnaire was highly correlated with the Willingness to Screen for AD scale ($r = 0.70, p < .01$). Due to this significant correlation, further analyses were performed using the Willingness to Screen for AD scale only.

5. Correlations among Main Outcome Measures

Correlations were run among the main study measures (Table 5). AD Anxiety and Willingness to Screen were significantly related to each other. AD Knowledge and AD Anxiety were not significantly correlated with each other, and AD Knowledge and Trait Anxiety were not significantly correlated with each other. As discussed above, AD Anxiety and Trait Anxiety were significantly correlated with each other, but were kept separate in primary analyses. Descriptive statistics for AD Knowledge, Willingness to Screen for AD, Trait Anxiety, and AD Anxiety are presented in Table 6.

6. Demographic Differences

a. Experience with AD

The variable 'Experience with AD' was created based on four demographic items: (1) whether the participant had a family history of AD in their family, (2) whether they currently had a family member with AD, (3) whether they had any friends with AD, or (4) whether they had ever been a caregiver for someone with AD. If the participant answered 'yes' to any of the above items, they were included in the 'Experience with AD' variable, so that this variable reflected any participant that had had some type of experience with

persons with AD. Half of the participants had no experience with AD ($n = 45$), and half had experience with AD ($n = 45$). Six participants were not considered for the 'Experience with AD' variable due to missing data. An independent means t-test revealed no significant ($p < .05$) differences between participants with and without experience with AD on Trait Anxiety, AD Knowledge, Willingness to Screen for AD, or AD Anxiety (Table 7).

b. Order of Measures

Some participants completed the AD Knowledge quiz before filling out the AD Anxiety questionnaire (Order 1, $n = 61$) while other participants filled out the AD Anxiety questionnaire before completing the AD Knowledge quiz (Order 2, $n = 35$). An independent means t-test revealed no significant ($p < .05$) differences between participants in the Order 1 group versus those in the Order 2 group on Trait Anxiety, AD Knowledge, Willingness to Screen for AD, or AD Anxiety (Table 8).

c. Paper versus Online Data Collection

The majority of participants filled out the survey electronically through a survey website ($n = 93$), while a small amount filled out the paper version of the survey in person ($n = 3$), thus no analyses were performed to compare potential differences between the different formats of data collection.

B. Primary Analyses

Primary analyses were multiple regressions to test the relationships between AD Knowledge, Trait Anxiety, AD Anxiety, and Willingness to Screen for AD. To test the first hypothesis (i.e., that greater knowledge would predict greater willingness to screen),

a regression analysis was run on the association between AD Knowledge and Willingness to Screen.

$$\text{Willingness} = a + b1(\text{AD Knowledge}) + \text{Error}$$

AD Knowledge alone was not a significant predictor of Willingness to Screen for AD ($B = 0.78, p > .05$). The hypothesis that greater knowledge would predict greater willingness to screen was not supported.

To test the second hypothesis (i.e., that more anxiety would predict less willingness to screen), a regression analysis was run on the association between AD Anxiety and Willingness to Screen.

$$\text{Willingness} = a + b1 (\text{Anxiety}) + \text{Error}$$

AD Anxiety was a significant predictor of Willingness to Screen for AD ($B = 0.25, p < .05$). More AD anxiety was associated with more willingness to screen for AD. In contrast, a regression analysis on the association between Trait Anxiety and Willingness to Screen indicated that Trait Anxiety was not a significant predictor of Willingness to Screen for AD ($B = -0.06, p > .05$). Thus, the second hypothesis that more anxiety would predict less willingness to screen was partially supported. While trait anxiety was not significantly associated with willingness to screen, AD anxiety in particular was significantly related to willingness to screen and it was associated with *more* willingness to screen.

The third and most novel hypothesis was that anxiety would moderate the relationship between AD Knowledge and Willingness to Screen. A moderated multiple regression determined how AD Knowledge, AD Anxiety, and the interaction between AD Knowledge and AD Anxiety predicted Willingness to Screen; these factors were entered in a blocked manner, one after the other (Table 9). AD Knowledge was not significantly

associated with Willingness to Screen. AD Anxiety was significantly associated with Willingness to Screen, after controlling for AD Knowledge. The interaction between AD Knowledge and AD Anxiety was of primary interest and this factor was a significant predictor of Willingness to Screen, after controlling for AD Knowledge and AD Anxiety.

C. Post-hoc Analyses

To interpret the significant interaction between AD Anxiety and AD Knowledge scores on Willingness to Screen for AD, a simple slopes analysis was performed following Aiken and West (1991). Amount of AD Knowledge was regressed separately on Willingness to Screen for AD for lesser (one standard deviation below the mean), and greater (one standard deviation above the mean) amounts of AD Anxiety as measured by total scores on the AD Anxiety scale.

Individuals with greater anxiety about AD showed a significant negative relationship between AD Knowledge scores and Willingness to Screen for AD, $B = -0.73$, $p < .01$. In contrast, individuals with lesser anxiety about AD showed a significant positive relationship between AD knowledge and willingness to screen for AD, $B = 2.40$, $p < .01$. This interaction is illustrated in Figure 1.

A moderated multiple regression was performed using Trait Anxiety as the anxiety measure. These variables were entered in a blocked manner, one after the other (Table 10). AD Knowledge was not significantly associated with Willingness to Screen. Trait Anxiety was not significantly associated with Willingness to Screen, after controlling for AD Knowledge. The interaction between AD Knowledge and Trait Anxiety was not a significant predictor of Willingness to Screen, after controlling for AD Knowledge and Trait Anxiety.

CHAPTER VII

DISCUSSION

A. Summary of Current Study Results

The current study determined how anxiety about AD moderates the association between knowledge about AD and willingness to screen for AD. Results indicated that knowledge has differential effects on willingness to screen based on levels of anxiety. When individuals had less AD anxiety than average, their willingness to screen increased as their amount of AD knowledge increased. In contrast, for participants with relatively more anxiety about AD, their willingness to screen decreased as their amount of AD knowledge increased.

B. Interaction between AD Knowledge and AD Anxiety

A focus of AD research is to increase general awareness and knowledge about AD to raise screening and early detection rates (e.g. Boustani et al., 2003; Devlin et al., 2007), but older adults have anxiety about AD (Boustani et al., 2003; Corner & Bond, 2004; Devlin et al., 2007) that may impact how knowledge affects willingness to screen. Knowledge about AD is multifaceted and includes information about treatment options, course, and severity of the disease (Ayalon & Arean, 2004). Even though early detection of AD is shown to be beneficial for patients and caregivers and can lead to effective active management of the disease (Connell et al., 2009), current drug treatments have limited efficacy at treating the symptoms of AD and cannot reverse the effects of the disease. Older adults who know about this information may be inclined to alleviate their anxiety about AD by avoiding screening for the disease. That is, perhaps individuals with

greater AD knowledge suspect that a diagnosis of AD would not benefit them in any way, and are thus less willing to screen. Adult children of parents with AD may represent this group. Even though adult children have knowledge about AD through their experience with the disease, they express an avoidance of the disease and report that they would delay getting a memory evaluation, even if they were experiencing memory problems (Corner & Bond, 2004). After witnessing AD in a parent, perhaps these adult children have both greater knowledge and greater anxiety about the disease and do not want to know if they have it themselves. Future studies should continue to explore the interplay between knowledge and anxiety in family members of persons with AD and their healthcare decisions. A possible study could involve measuring knowledge, anxiety, and willingness to screen in a sample comprised of an equal amount of participants who have a family member with AD and participants with no family experience with the disease, in order to compare how knowledge and anxiety about AD effects each of these groups of participants differently.

The current study indicates that if information is presented to increase knowledge about AD, then perhaps there should be corresponding information aimed at reducing anxiety and fear about the disease. Devlin et al. (2007) suggest that providing adults with information about treatment options and education and counseling about AD could encourage people to seek an AD diagnosis. For older adults who have less knowledge about AD, a different type of campaign should be designed. The theory of “fear appeals” proposes that a certain amount of fear can be utilized to raise anxiety and motivate people to engage in healthy behavior (Tanner et al., 1991). Results indicate that a campaign utilizing fear appeals to increase anxiety about AD should not also focus on increasing

knowledge about the disease, as that may mitigate the effectiveness of the fear appeal. A campaign designed to increase disease anxiety so that it becomes a motivator may be most effective only when targeting a group of individuals who do not have prior experience with and knowledge about AD. Overall, for each individual, there may be ideal levels of anxiety and knowledge that can be used together to produce the most effective AD awareness campaigns that will motivate individuals to seek treatment.

C. Main Effect Finding of AD Anxiety

Along with a moderation effect of anxiety on the relationship between AD knowledge and willingness to screen, there was also a main effect finding that AD anxiety was significantly associated with willingness to screen for AD, though in the opposite direction than expected. Without taking AD knowledge into account, participants who had more anxiety about AD were more willing to screen for the disease. This result was unexpected given previous findings. For example, Corner and Bond (2004) found that older adults' fear and anxiety about AD influenced many of them to avoid thinking about the possibility of having AD. Similarly, older adults reported that they would avoid having a memory evaluation because of their fears about the disease (Devlin et al., 2007). Based on these compelling studies, it was expected that participants with more AD anxiety would be less willing to screen for AD. One possible explanation for the unexpected direction of the relationship between anxiety and willingness to screen could be that the participants in the study conducted by Corner and Bond (2004) had a mean age of 82, while the current study sample was made up of generally younger older adults, with a mean age of 62. Corner and Bond (2004) speculate that avoidance of talking or thinking about AD may increase with age. Perhaps our sample of younger older

persons represents individuals who are affected by disease anxiety differently than an older age group of older persons.

It may be that for some individuals, anxiety may be motivating, rather than contributing to disease avoidance. Individuals who have anxiety about AD may become hypervigilant about checking for symptoms of the disease (Hodgson & Cutler, 2003; Cutler & Hodgson, 1996), and may be more willing to undergo evaluation and screening for AD. Cutler and Hodgson (1996) have conducted extensive research on the concept of “anticipatory dementia,” in which older adults have anxiety about memory changes and about developing AD in their lifetime. For these individuals, having some anxiety and fear about AD influences them to have memory symptoms checked and to seek screening for AD. Hodgson and Cutler (2003) propose that individuals with a higher level of education are more likely to have read or heard about AD and its symptoms, and therefore may be more likely to symptom seek for the disease in themselves. Hodgson and Cutler (2003) also found that holding higher-prestige occupations was related to more concern about developing AD in the future, suggesting that the thought of AD is more threatening to adults who hold cognitively-oriented jobs. The current study sample was highly educated and had an above average mean income. It is possible that they represented a group of adults who are more likely to be hyper-vigilant if they have anxiety about AD, and therefore express more willingness to screen.

D. Exploring the Role of AD Knowledge

Prior studies found that greater knowledge about AD was related to more willingness to screen for the disease (Galvin et al., 2007; Werner, 2003b; Ayalon & Arean, 2004; Werner, 2004). In the current study, there was no main effect for AD

knowledge; it was not significantly associated with willingness to screen for AD. Galvin et al. (2007) found that older adults with more knowledge about AD had a higher perceived susceptibility of developing the disease, as well as a higher perceived benefit to treatment. They report that it was increases in these types of information that contributed to a higher intention to screen. Coupled with the current study's findings, perhaps it is not simply knowledge about AD that is related to willingness to screen, but the effect that AD knowledge has on older adults' perceived vulnerability and benefits of early detection of AD. Edwards et al. (2000) found that while most respondents in their study knew that there was no cure for AD, they had significant misconceptions about available services for the disease. The authors speculate that having knowledge about services and treatment options increases personal awareness of the disease and enables service and treatment use. Future studies should further explore the roles that various types of knowledge about AD play in older adults' thinking about the effects of the disease. Perhaps simply knowing facts about AD is less important than knowing specific key aspects of the disease, such as treatment options.

To our knowledge, no previous studies have used the ADKS as the primary measure of knowledge about AD when measuring the relationship between knowledge and willingness to screen for AD. Since the ADKS was developed as a general measure of AD knowledge (Carpenter, 2009), as opposed to a measure of multiple components of knowledge about AD, it may not have captured the differential effects of specific AD knowledge on willingness to screen. Future studies should explore the use of a range of knowledge measures with more specific content, to determine whether the knowledge measured by some is more related to willingness to screen than in others.

E. Limitations

Our sample was comprised of mostly Caucasian, highly educated, and middle-class older adults. Additionally, the majority of data were collected through an online survey site, which requires access to the internet and adequate computer skills. Thus, our sample may represent a specific cohort of older adults who fit those criteria. It is difficult to generalize these findings to the general population. Lack of representativeness is a limitation.

Because of a lack of previous research on anxiety about AD, an AD anxiety questionnaire was created for this study. Additionally, a questionnaire to measure willingness to screen for AD was also created for this study. These are limitations since we could not be sure of these scales' reliability or validity in other samples. We hope our AD anxiety and willingness measures will continue to be developed and refined in future research.

F. Conclusion and Future Research

While previous studies have identified that older adults have fear about AD (Corner & Bond, 2004; Devlin et al., 2007), the current study provided a specific assessment of AD anxiety. AD anxiety was a significant predictor of willingness to screen for AD. In addition, this anxiety moderated the effect of knowledge about AD on willingness to screen for AD. Thus, AD anxiety is an important construct to understand when developing effective health campaigns and screening programs for AD.

Future studies should further develop and refine the AD Anxiety questionnaire to facilitate exploration of this construct. AD anxiety represents a specific type of anxiety that had a different effect than trait anxiety on adults' screening behavior. More studies

including measures of anxiety about AD, trait, and state anxiety may reveal more interesting insight into what influences decisions to screen or not for AD. Given that adults with more knowledge about AD may be less willing to screen for the disease when they have more anxiety about it, future studies should further examine the effect of knowledge on willingness to screen. It is possible that different aspects of knowledge about AD, such as symptoms, treatment, or personal experience affect older adults' thoughts and feelings about the disease in different ways. By determining the specific effects of both knowledge and anxiety about AD, we can understand how these factors influence older adult's willingness to screen for the disease so that effective healthcare interventions can be implemented.

Table 1: Demographic Characteristics of Participants (N = 96)

Characteristic	<i>n</i>	<i>%</i>
Gender		
Male	17	17.7
Female	79	82.3
Race		
White	94	97.9
American Indian, Alaska Native	1	1
Education		
High School Graduate/ GED	3	3.1
Partial College	20	20.8
College Graduate	23	24
Master's Degree	32	33.3
Doctoral Degree, MD, or equivalent	18	18.8
Income (Dollars)		
0-15,000	5	5.2
15,000-30,000	14	14.6
30-000-45,000	17	17.7
45,000-60,000	19	19.8
60,000-75,000	7	7.3
Above 75,000	31	32.4

Table 2: Group Differences for Trait Anxiety, AD Knowledge, Willingness to Screen for AD, and AD Anxiety Between Genders

Males

Variable	<i>n</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>df</i>
1. Trait Anxiety	16	21.16	7.24	-0.57	90
2. AD Knowledge	16	24.38	3.40	1.17	85
3. Willingness	16	30.06	4.77	0.85	90
4. AD Anxiety	16	15.50	4.18	1.30	87

Females

1. Trait Anxiety	76	22.17	6.36	-0.57	90
2. AD Knowledge	71	23.49	2.56	1.17	85
3. Willingness	76	28.71	5.95	0.85	90
4. AD Anxiety	73	13.83	4.75	1.30	87

Table 3: Factor Loadings From Principal Components Analysis: Communalities, Eigenvalues, and Percentages of Variance for Items of the AD Anxiety Questionnaire (continued on to next page)

Item	Factor Loading	
	1	Communality
1. The older I become the more I worry about developing AD	.78	.69
2. The thought of AD makes me anxious	.71	.66
3. I avoid thinking about AD because it worries me	.65	.52
4. I find it hard to stop worrying about AD	.60	.73
5. I'm afraid that my life would have no meaning if I had AD	.60	.71
6. I worry that if I developed AD I would feel embarrassed and foolish	.56	.45
7. I worry when I experience small memory slip-ups	.55	.69
8. I am uncomfortable around individuals with AD	.45	.79
9. I feel myself get anxious when I am around individuals with AD	.42	.83
10. Developing AD would ruin my life	.41	.59
11. My heart races when I think about forgetting who are my friends and family	.37	.72
12. AD is something that people my age should be concerned about	.34	.47
13. I have trouble breathing when I think about AD	.33	.61
14. I expect that I would still feel the same about myself as I do now if I had AD.	-.18	.76
15. I would be able to adapt well if I developed AD	-.16	.79

Eigenvalue	4.47
% of variance	29.82

Table 4: Factor Loadings from Principal Component Factor Analysis: Communalities, Eigenvalues, and Percentage of Variance for Items of the Willingness to Screen for Alzheimer’s Disease Questionnaire

Item	<u>Factor Loading</u>	
	1	
Communality		
1. Rate how willing you would be to undergo a brief screening test for AD if you felt you were experiencing memory problems	.80	.64
2. I would want to know as early as possible if I had AD	.89	.76
3. If my primary care doctor was offering free screenings for AD, I would gladly do one	.87	.76
4. Imagine a hypothetical situation in which you are suffering from signs of AD, rate how much you agree with this statement: I would seek professional help	.80	.64
5. If my doctor told me I was experiencing signs of AD, I would want to get them evaluated as soon as possible	.85	.72
6.If I noticed a friend not being able to complete daily tasks, I would urge them to talk to their doctors about these memory and functional changes	.31	.09
7. I would like my doctor to give me a screening test for AD at every check up	.50	.25
8. Please rate how likely you think it is that you will develop AD at some point in the future.	-.07	.01
Eigenvalue	4.22	
% of variance	52.76	

Table 5: Correlations among Trait Anxiety, Willingness to Screen for AD, AD Knowledge, and AD Anxiety

Variable	Trait Anxiety	Willingness	AD Knowledge
Willingness	-0.06		
AD Knowledge	-0.18	0.14	
AD Anxiety	0.39*	0.22**	-.07

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

Table 6: Descriptive Statistics of Main Study Variables

Variable	<i>n</i>	<i>M</i>	<i>SD</i>	<i>Minimum</i>	<i>Maximum</i>	<i>Cronbach's Alpha</i>
Trait Anxiety	92	21.99	6.49	12.50	37	0.88
AD Knowledge	87	23.66	2.74	17.00	29	0.79
AD Anxiety	89	16.98	5.13	7.00	30	0.82
Willingness to Screen for AD	92	28.95	5.76	7.00	35	0.87

Table 7: Group Differences for Trait Anxiety, AD Knowledge, Willingness to Screen for AD, and AD Anxiety Between Experience and No Experience with AD

Variable	<u>No Experience with AD</u>				
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>df</i>
1. Trait Anxiety	42	22.23	5.88	0.35	84
2. AD Knowledge	39	23.87	2.75	0.21	80
3. Willingness	41	30.00	4.22	1.75	84
4. AD Anxiety	41	12.86	4.41	-1.91	82
	<u>Experience with AD</u>				
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>df</i>
1. Trait Anxiety	44	21.73	7.18	0.35	84
2. AD Knowledge	43	23.74	2.68	0.21	80
3. Willingness	45	27.80	6.95	1.75	84
4. AD Anxiety	43	15.07	4.78	-1.91	82

Table 8: Group Differences for Trait Anxiety, AD Knowledge, Willingness to Screen for AD, and AD Anxiety Between Orders

Order 1

Variable	<i>n</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>df</i>
1. Trait Anxiety	60	21.62	6.38	-0.76	90
2. AD Knowledge	59	23.81	2.90	0.78	85
3. Willingness	61	28.82	6.13	-0.29	90
4. AD Anxiety	56	14.33	4.62	0.69	87

Order 2

	<i>n</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>df</i>
1. Trait Anxiety	32	22.70	6.74	-0.76	90
2. AD Knowledge	28	23.32	2.37	0.78	85
3. Willingness	31	29.19	5.04	-0.29	90
4. AD Anxiety	33	13.74	4.83	0.69	87

Table 9: Willingness to Screen Moderated Regression: Predicting Willingness to Screen from AD Knowledge and AD Anxiety

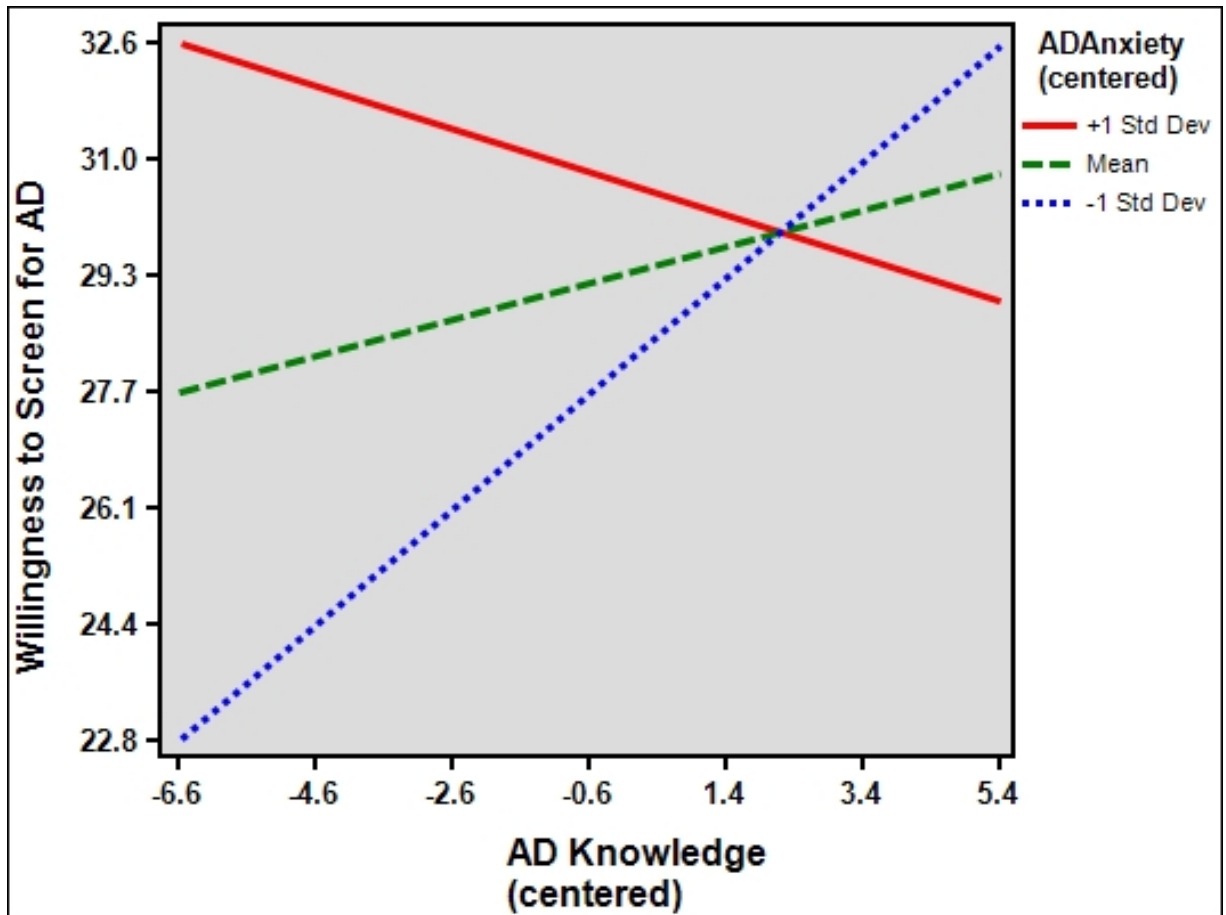
Dependent Variable	Independent Variables	<i>B</i>	<i>SE</i>	<i>Beta</i>	<i>t</i>
Block 1	AD Knowledge	0.32	0.21	0.17	1.52
	$R^2 = 0.03, F(1, 80) = 2.30$				
Block 2	AD Knowledge	0.35	0.21	.018	1.68
	AD Anxiety	0.24	0.12	0.22	2.03*
	$\Delta R^2 = 0.07, F(2, 79) = 3.27^*$				
Block 3	AD Knowledge	0.31	0.20	0.16	1.53
	AD Anxiety	0.24	0.11	0.22	2.14*
	Knowledge*Anxiety	-1.57	0.57	-0.29	-2.73**
	$\Delta R^2 = 0.16, F(3, 78) = 4.84^{**}$				

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

Table 10: Willingness to Screen Moderated Regression: Predicting Willingness to Screen from AD Knowledge and Trait Anxiety

Dependent Variable	Independent Variables	<i>B</i>	<i>SE</i>	<i>Beta</i>	<i>t</i>
Block 1	AD Knowledge	0.78	0.60	0.14	1.30
	$R^2 = 0.02, F(1, 84) = 1.70$				
Block 2	AD Knowledge	0.77	0.61	0.14	1.25
	Trait Anxiety	-0.07	0.62	-0.01	-0.11
	$\Delta R^2 = 0.00, F(2, 83) = 0.84$				
Block 3	AD Knowledge	0.73	0.62	0.13	1.18
	Trait Anxiety	-0.08	0.62	-0.01	-0.13
	Knowledge*Anxiety	0.63	0.73	0.09	0.86
	$\Delta R^2 = 0.01, F(3, 82) = 0.81$				

Figure 1: Moderated Regression: Predicting Willingness to Screen from AD Knowledge and AD Anxiety



APPENDIX A

BRIEF SCREENING QUESTIONNAIRE

Please answer each of the following questions.

1. Do you currently have a diagnosis of Mild Cognitive Impairment?

Yes No

2. Do you currently have a diagnosis of Alzheimer's disease, or any other type of dementia?

Yes No

APPENDIX B

DEMOGRAPHIC QUESTIONNAIRE

1. What is your age?

2. What is your gender?

0) M

1) F

3. Are you retired or employed?

0) Retired

1) Employed

If employed, do you work full time or part time?

0) Full time

1) Part time

4. Please circle which of the following best describes your current income:

0) 0-15,000

1) 15,000-30,000

2) 30,000-45,000

3) 45,000-60,000

4) 60,000-75,000

5) Above 75,000

5. What is the highest level of education you have completed? (Please circle one)

- 0) Less than 7 years of school (6th grade or less)
- 1) Junior High School (completed grades 7, 8, or 9)
- 2) Partial High School (completed grade 10 or 11)
- 3) High School Graduate or GED
- 4) Partial college
- 5) College Graduate
- 6) Master's Degree
- 7) Doctoral Degree, or MD, or the equivalent

6. Are you Hispanic or Latino?

- 0) Yes
- 1) No
- 2) Don't know/Not sure

7. Which one of these groups would you say best represents your race?

- 0) White
- 1) Black or African American
- 2) Asian
- 3) Native Hawaiian or Other Pacific Islander
- 4) American Indian, Alaska Native
- 5) Other (specify)
- 6) Don't know/Not sure

8. What is your marital status? (Please circle one)

- 0) Married
- 1) Widowed
- 2) Divorced
- 3) Separated
- 4) Never married

5) A member of an unmarried couple

9. Is there a family history of Alzheimer's disease in your family?

0) Yes

1) No

10. Does anyone in your family currently have Alzheimer's disease?

0) Yes

1) No

11. Do you have any friends with Alzheimer's disease?

0) Yes

1) No

12. Have you ever been a caregiver for someone with Alzheimer's disease?

0) Yes

1) No

If yes, please describe the nature of your relationship:

13. Do you have any concerns about your memory functioning at the present time?

0) Yes

1) No

14. How would you rate your overall health at the present item?

0) Extremely poor

1) Very poor

2) Average

3) Very Good

4) Excellent

15. Have you ever been diagnosed and/or treated with a psychiatric or mental disorder?

0) Yes

1) No

16. Have you ever had a memory evaluation before?

0) Yes

1) No

If yes, please describe where and when:

17. Do you see your doctor for regular check-ups?

0) Yes

1) No

APPENDIX C

WILLINGNESS TO SCREEN FOR CHRONIC DISEASES

On a scale of 1-10, with 1 being not at all willing and 10 being completely willing, please rate how willing you would be to screen for the following diseases if you felt you were experiencing some initial signs of the disease:

Cancer

1 2 3 4 5 6 7 8 9 10

Heart Disease

1 2 3 4 5 6 7 8 9 10

Diabetes

1 2 3 4 5 6 7 8 9 10

Parkinson's Disease

1 2 3 4 5 6 7 8 9 10

Alzheimer's disease

1 2 3 4 5 6 7 8 9 10

Arthritis

1 2 3 4 5 6 7 8 9 10

Osteoporosis

1 2 3 4 5 6 7 8 9 10

Hypertension

1 2 3 4 5 6 7 8 9 10

Glaucoma

1 2 3 4 5 6 7 8 9 10

APPENDIX D

KNOWLEDGE QUIZ

Please read each statement carefully and decide whether you think it is true or false, by circling either “T” if you think the statement is all true or mostly true, and “F” if you think the statement is all false or mostly false.

1. People with Alzheimer's disease are particularly prone to depression. T F
2. It has been scientifically proven that mental exercise can prevent a person from getting Alzheimer's disease. T F
3. After symptoms of Alzheimer's disease appear, the average life expectancy is 6 to 12 years. T F
4. When a person with Alzheimer's disease becomes agitated, a medical examination might reveal other health problems that caused the agitation. T F
5. People with Alzheimer's disease do best with simple, instructions given one step at a time. T F
6. When people with Alzheimer's disease begin to have difficulty taking care of themselves, caregivers should take over right away. T F
7. If a person with Alzheimer's disease becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day. T F
8. In rare cases, people have recovered from Alzheimer's disease T F
9. People whose Alzheimer's disease is not yet severe can benefit from psychotherapy for depression and anxiety. T F

10. If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's disease. T F
11. Most people with Alzheimer's disease live in nursing homes. T F
12. Poor nutrition can make the symptoms of Alzheimer's disease worse. T F
13. People in their 30s can have Alzheimer's disease. T F
14. A person with Alzheimer's disease becomes increasingly likely to fall down as the disease gets worse. T F
15. When people with Alzheimer's disease repeat the same question or story several times, it is helpful to remind them that they are repeating themselves. T F
16. Once people have Alzheimer's disease, they are no longer capable of making informed decisions about their own care. T F
17. Eventually, a person with Alzheimer's disease will need 24-hour supervision. T F
18. Having high cholesterol may increase a person's risk of developing Alzheimer's disease. T F
19. Tremor or shaking of the hands or arms is a common symptoms in people with Alzheimer's disease. T F
20. Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease. T F
21. Alzheimer's disease is one type of dementia. T F
22. Trouble handling money or paying bills is a common early symptoms of Alzheimer's disease. T F

23. One symptom that can occur with Alzheimer's disease is believing that other people are stealing one's things. T F
24. When a person has Alzheimer's disease, using reminder notes is a crutch that can contribute to decline. T F
25. Prescription drugs that prevent Alzheimer's disease are available. T F
26. Having high blood pressure may increase a person's risk of developing Alzheimer's disease. T F
27. Genes can only partially account for the development of Alzheimer's disease. T F
28. It is safe for people with Alzheimer's disease to drive, as long as they have a companion in the car at all times. T F
29. Alzheimer's disease cannot be cured. T F
30. Most people with Alzheimer's disease remember recent events better than things that happened in the past. T F

APPENDIX E

ANXIETY ABOUT AD QUESTIONNAIRE

Please read each of the following statements carefully and rate how much you agree with each statement, ranging from “Strongly disagree” to “Strongly Agree”.

1. I find it hard to stop worrying about AD

Strongly disagree Disagree Don't know Agree Strongly Agree

2. I worry when I experience small memory slip ups

Strongly disagree Disagree Don't know Agree Strongly Agree

3. I worry that if I developed AD, I would feel embarrassed and foolish

Strongly disagree Disagree Don't know Agree Strongly Agree

4. Developing AD would ruin my life

Strongly disagree Disagree Don't know Agree Strongly Agree

5. I am uncomfortable around individuals with AD

Strongly disagree Disagree Don't know Agree Strongly Agree

6. I would be able to adapt well if I developed AD

Strongly disagree Disagree Don't know Agree Strongly Agree

7. AD is something that people my age should be concerned about

Strongly disagree Disagree Don't know Agree Strongly Agree

8. I have trouble breathing when I think about AD

Strongly disagree Disagree Don't know Agree Strongly Agree

9. I feel myself get anxious when I am around individuals with AD

Strongly disagree Disagree Don't know Agree Strongly Agree

10. My heart races when I think about forgetting who are my friends and family

Strongly disagree Disagree Don't know Agree Strongly Agree

11. The older I become, the more I worry about developing AD

Strongly disagree Disagree Don't know Agree Strongly Agree

12. I'm afraid that my life would have no meaning if I had AD

Strongly disagree Disagree Don't know Agree Strongly Agree

13. I expect that I would still feel the same about myself as I do now if I had AD

Strongly disagree Disagree Don't know Agree Strongly Agree

14. The thought of AD makes me anxious

Strongly disagree Disagree Don't know Agree Strongly Agree

15. I avoid thinking about AD because it worries me.

Strongly disagree Disagree Don't know Agree Strongly Agree

16. Please describe what comes to mind when you think about AD.

17. Please describe how you feel about the possibility of developing AD at some point in the future.

APPENDIX F

STATE TRAIT ANXIETY SCALE

Directions:A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate value to the right of the statement to indicate how you feel *generally* on a scale from one to four, with “1” indicating that you feel that way “Not at all,” “2” that you feel that way “Somewhat,” “3” that you feel that way “Moderately So” and “4” that you feel that way “Very much So.” There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

- | | | | | |
|--|---|---|---|---|
| 1. I feel calm..... | 1 | 2 | 3 | 4 |
| 2. I feel secure..... | 1 | 2 | 3 | 4 |
| 3. I am tense..... | 1 | 2 | 3 | 4 |
| 4. I feel strained..... | 1 | 2 | 3 | 4 |
| 5. I feel at ease..... | 1 | 2 | 3 | 4 |
| 6. I feel upset..... | 1 | 2 | 3 | 4 |
| 7. I am presently worrying over possible misfortunes...1 | 1 | 2 | 3 | 4 |
| 8. I feel satisfied..... | 1 | 2 | 3 | 4 |
| 9. I feel frightened..... | 1 | 2 | 3 | 4 |
| 10. I feel comfortable..... | 1 | 2 | 3 | 4 |
| 11. I feel self-confident..... | 1 | 2 | 3 | 4 |
| 12. I feel nervous..... | 1 | 2 | 3 | 4 |
| 13. I am jittery..... | 1 | 2 | 3 | 4 |
| 14. I feel indecisive..... | 1 | 2 | 3 | 4 |
| 15. I am relaxed..... | 1 | 2 | 3 | 4 |
| 16. I feel content..... | 1 | 2 | 3 | 4 |
| 17. I am worried..... | 1 | 2 | 3 | 4 |

18. I feel confused.....	1	2	3	4
19. I feel steady.....	1	2	3	4
20. I feel pleasant.....	1	2	3	4

APPENDIX G

TEN-ITEM PERSONALITY INVENTORY

Here are a number of personality traits that may or may not apply to you. Please write a number next to each statement to indicate the extent to which you agree or disagree with that statement. You should rate the extent to which the pair of traits applies to you, even if one characteristic applies more strongly than the other.

Disagree strongly	Disagree moderately	Disagree a little	Neither agree nor disagree	Agree a little	Agree moderately	Agree strongly
1	2	3	4	5	6	7

I see myself as:

1. _____ Extraverted, enthusiastic.
2. _____ Critical, quarrelsome.
3. _____ Dependable, self-disciplined.
4. _____ Anxious, easily upset.
5. _____ Open to new experiences, complex.
6. _____ Reserved, quiet.
7. _____ Sympathetic, warm.
8. _____ Disorganized, careless.
9. _____ Calm, emotionally stable.
10. _____ Conventional, uncreative.

APPENDIX H

WILLINGNESS TO SCREEN FOR AD

1. On a scale of 1-10, with 1 being not at all willing and 10 being completely willing, please rate how willing you would be to undergo a brief screening test for Alzheimer's disease if you felt you were experiencing memory problems.

1 2 3 4 5 6 7 8 9 10

Please rate how much you agree with the following statements.

2. I would want to know as early as possible if I had AD.

Strongly disagree Disagree Don't know Agree Strongly Agree

3. If my primary care doctor was offering free screenings for AD, I would gladly do one

Strongly disagree Disagree Don't know Agree Strongly Agree

4. For the following question, please imagine a hypothetical situation in which you were suffering from signs of AD, and then rate how much you agree with the following statement: I would seek professional help (such as from my primary care doctor, family physician, psychiatrist, psychologist, neurologist, social worker).

Strongly disagree Disagree Don't know Agree Strongly Agree

5. If I noticed a friend not being able to complete daily tasks and forgetting appointments and peoples' names, I would urge them to talk to their doctors about these memory and functional changes.

Strongly disagree Disagree Don't know Agree Strongly Agree

6. If my doctor told me I was experiencing signs of Alzheimer's disease, I would want to get them evaluated as soon as possible.

Strongly disagree Disagree Don't know Agree Strongly Agree

7. I would like my doctor to give me a screening test for Alzheimer's disease at every check-up.

Strongly disagree Disagree Don't know Agree Strongly Agree

8. On a scale of 1 to 10, with 1 being extremely unlikely, and 10 being extremely likely, please rate how likely you think it is that you will develop Alzheimer's disease at some point in the future.

1 2 3 4 5 6 7 8 9 10

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