

**Perceived Threat of Alzheimer's Disease and Help-Seeking Behavior  
in Older Adults with Memory Complaints**

by

Jenny E. Ostergren

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
(Health Behavior and Health Education)  
in the University of Michigan  
2017

Doctoral Committee:

Associate Professor J. Scott Roberts, Chair  
Professor Cathleen Connell  
Research Scientist Steven Heeringa  
Professor Carlos Mendes de Leon

© Jenny E. Ostergren 2017

## **DEDICATION**

In loving memory of my grandparents, Robert Ostergren, Sr., and Lorraine Ostergren, who taught me the value of persistence.

## ACKNOWLEDGEMENTS

This dissertation would not have been possible without the encouragement, support, and guidance of so many individuals. Foremost, I would like to express my sincere gratitude to my advisor and committee chair, Dr. Scott Roberts, for his expertise, guidance, patience, and unwavering support throughout my Ph.D. studies and the process of writing this dissertation. Thank you, Scott, for seeing the potential in me and always being there. I could not have asked for a better advisor and mentor.

I would also like to express my thanks and appreciation to my committee members, Dr. Cathleen Connell, Dr. Steven Heeringa, and Dr. Carlos Mendes de Leon, for their expertise, insightful comments, and encouragement, which helped to improve and strengthen my dissertation work. I am grateful for the time and care each of you put into providing constructive feedback on my dissertation papers and guidance on my statistical analyses.

A very special thank you to the HBHE Genetics Research Group, Lan Le, Natalie Bartnik, Dr. Michele Gornick, and Wendy Uhlmann, for all their support, help, and valuable feedback throughout my time in the program. You've helped to expand my knowledge and research skills, and my work is much stronger thanks to you.

I would also like to thank my fellow HBHE doctoral students for their advice, encouragement, and friendship over the years. In particular, I want to thank Jonathon Vivoda for his valuable mentorship and advice throughout my time in the program. Thanks also to Aresha Martinez, Elizabeth Mosley, and Rebecca Leinberger for being the most awesome cohort of

strong and brilliant ladies I know. You inspire me every day, and I'm grateful for your friendship and support.

The academic and financial support I received from the Department of Health Behavior and Health Education has played an integral role in my academic success. I'd like to thank the department for supporting my Ph.D. studies through a Victor Strecher Scholarship, Summer Writing Awards, and a Departmental One-Term Dissertation Fellowship. I was also very fortunate to be the recipient of a Predoctoral Traineeship in Public Health and Aging, which supported my dissertation research for two years. I'd like to thank Dr. Carlos Mendes de Leon for the training and research support I received during those years, which has been essential in getting me to this point.

Finally, I'd like to thank my amazing family and friends who stood by me and supported me on this journey. My husband, Nick Gutierrez, has been my rock and a constant source of motivation and inspiration through both the good and tough times in the program. Thank you, Nick, for believing in me and keeping me grounded. I'd like to thank my parents, Robert and Carol Ostergren, for always going above and beyond to support my passions and ambitions, and my brother Jason Ostergren and sister-in-law Maisha Ostergren for housing me in Ann Arbor and providing moral support and encouragement. Thank you also to my brother Brian Ostergren and sister-in-law Qiaolan Wan, and to my good friends Yichen and Jeffrey Kuan, for supporting and encouraging me throughout this process and in life in general.

## TABLE OF CONTENTS

DEDICATION	ii
ACKNOWLEDGEMENTS	iii
LIST OF TABLES	vi
LIST OF FIGURES	vii
ABSTRACT	viii
CHAPTER	
1. Introduction	1
2. Factors Influencing Help-Seeking among Older Adults with Dementia Concerns: A Systematic Review	15
3. The Influence of Psychosocial and Cognitive Factors on Perceived Threat of Alzheimer’s Disease Among a Representative Sample of U.S. Adults	83
4. Demographic, Health Care Access, and Health Status Predictors of Help-Seeking Behavior for Subjective Memory Complaints among Older Adults	119
5. Conclusion	155

## LIST OF TABLES

<b>Table 2-1:</b>	Summary of Studies Identified in Systematic Review of Help-Seeking Behavior for SMCs (N = 61)	42
<b>Table 2-2:</b>	Background of Studies (N = 61)	74
<b>Table 2-3:</b>	Summary of Domains and Factors Related to Formal Help-Seeking	75
<b>Table 3-1:</b>	HRS Population Characteristics (N = 1,641)	105
<b>Table 3-2:</b>	Means, SE, and Score Range of Psychosocial and Cognitive Variables (N = 1,641)	106
<b>Table 3-3:</b>	Comparison of Linear Regression Results for Mean Composite Measure of Perceived AD Threat and “You believe you will get AD someday” (N = 1,625)	107
<b>Table 3-4:</b>	Bivariate Summary of Associations among Categorical Predictors of Perceived AD Threat (Chi-square tests of association; N = 1,641).	108
<b>Table 3-5:</b>	Bivariate Summary with Pearson Correlations for Perceived AD Threat and Psychosocial and Cognitive Predictors (N = 1,641)	109
<b>Table 3-6:</b>	Summary of Linear Regression Analysis of Perceived AD Threat (N= 1,625)	110
<b>Table 4-1:</b>	Comparison of Results from Multiple Imputation and Single Imputation Models	141
<b>Table 4-2:</b>	Unweighted Respondent Counts and Population Weighted Percentages of Demographic Characteristics for the BRFSS Population (N = 6,807)	142
<b>Table 4-3:</b>	Means, SE, and Score Range of Health Status and Health Care Access Variables (N = 6,807)	143
<b>Table 4-4:</b>	Bivariate Summary of Associations among Categorical Predictors of Help-Seeking Behavior (Chi-square tests of association; N = 6,807)	144
<b>Table 4-5:</b>	Bivariate Summary with Pearson Correlations for Help-Seeking Behavior and Health Status Predictors (N = 6,807)	146
<b>Table 4-6:</b>	Summary of Logistic Regression Analysis of Help-Seeking Behavior (N = 6,807)	147

## LIST OF FIGURES

<b>Figure 1-1:</b>	Conceptual Model of Perceived AD Threat and Help-seeking Behavior	10
<b>Figure 2-1:</b>	Flow Diagram	41
<b>Figure 3-1:</b>	Conceptual Model of Research Question 1: What are the significant psychosocial and cognitive factors associated with perceived AD threat?	112
<b>Figure 3-2:</b>	Conceptual Model of Research Question 2: Does family experience with AD moderate the relationship between cognitive factors and perceived AD threat?	113
<b>Figure 3-3:</b>	Moderating effect of personal experience with AD on the relationship between subjective memory complaints and perceived AD threat	114
<b>Figure 3-4:</b>	Moderating effect of personal experience with AD on the relationship between age group and perceived AD threat	115
<b>Figure 4-1:</b>	Conceptual Model for Research Study Question: What is the association between specific demographic factors, health care access, health status, and help seeking behavior for memory complaints?	148



## **ABSTRACT**

Alzheimer's disease (AD) is a chronic disorder with a high burden of suffering for affected individuals, their caregivers, families, and communities. An increased emphasis on early AD detection may benefit affected individuals and their caregivers, especially where disparities already exist in health care and outcomes, but may also unnecessarily heighten perceived AD threat among healthy older adults. Relatively few studies have examined predictors of perceived AD threat and help-seeking behavior among a large and diverse sample that is broadly representative of the U.S. adult population. Informed by health behavior theory, my dissertation 1) identifies factors that influence formal help-seeking for memory complaints through a systematic review of the literature, 2) examines psychosocial and cognitive predictors of perceived AD threat, an understudied construct related to help-seeking, among a nationally representative sample of U.S. adults from the Health and Retirement Study, and 3) explores demographic, health care access, and health status predictors of help-seeking among older adults with memory complaints using Behavioral Risk Factor Surveillance System data. Findings from the systematic review suggest that individual, interpersonal, and structural/policy level factors each play a key role in help-seeking. Multivariate analyses of perceived AD threat revealed that perceived threat was significantly higher for respondents aged 50-64 and 65-74 than for those  $\geq 75$ . Higher perceived threat was also associated with a family history of AD (compared to no experience), stronger beliefs that stress or genetics are important AD risk factors, more depressive symptoms, poorer self-rated memory, and lower cognitive function. Respondents with lower education levels were significantly less likely to seek help. Those who reported more

memory-related functional difficulty, more frequent days of poor mental health, and having a primary care provider, were more likely to seek help. These findings highlight the need for education and community outreach to raise awareness about early dementia symptoms, provide specific factors that health care providers should consider in clinical encounters, and highlight the need for careful initial cognitive screening of individuals with memory complaints. These findings also provide insight about the help-seeking process, and a starting point for interventions aimed at increasing timely AD diagnosis and treatment.

## **CHAPTER 1**

### **Introduction**

There are as many as 5.2 million Americans age 65 and older living with Alzheimer's disease (AD) (Alzheimer's Association, 2016; Hebert, Weuve, Scherr, & Evans, 2013). While some variation in prevalence estimates exists across studies (Brookmeyer et al., 2011), all studies suggest that, barring a breakthrough in preventive therapies, the prevalence of AD will escalate rapidly over the coming years as the number of older Americans continues to grow. By 2050, the number of people with AD may nearly triple (Hebert et al., 2013). Many agencies and organizations in the U.S. and worldwide have made early detection and diagnosis of dementia a public health priority (Alzheimer's Association & Centers for Disease Control and Prevention, 2013; U.S. Department of Health and Human Services, 2016; World Health Organization, 2012). Early detection may help to improve the quality of care and support received by patients and families, and reduce the substantial personal and societal burden of the disease. Nonetheless, many older adults with dementia, and their families, do not seek help in the early stages of the disease, contributing to a delay in diagnosis and treatment of the disease.

An early diagnosis of dementia can benefit affected individuals and their families by allowing more time for long-term planning, including making living arrangements, and sorting out financial and legal affairs. Early diagnosis can also improve timely access to treatments, care, and support services (de Vugt & Verhey, 2013; Relkin, 2000; World Health Organization, 2012). Pharmaceutical therapies, when started early, can lessen symptom severity and enhance quality

of life (National Institute on Aging, 2014). The societal costs associated with the disease may also be reduced with timely diagnosis, including costs incurred from hospitalizations due to disease-related catastrophic events (e.g., motor vehicle accidents) (Relkin, 2000; Weimer & Sager, 2009). One recent study found that older adults with probable dementia who have not received a diagnosis were more likely to engage in unsafe behaviors, like driving, preparing hot meals, managing finances and medications, and attending doctor visits alone, compared to older adults who had been diagnosed (Amjad, Roth, Samus, Yasar, & Wolff, 2016). Early initiation of treatment may also help to prolong time to institutional placement and disability, allowing individuals to spend more time at home in their communities and less time in a long-term care facility, thus reducing disease-related societal costs (Budd, Burns, Guo, L'Italien, & Lapuerta, 2011; Relkin, 2000; Weimer & Sager, 2009). Receiving an early evaluation for dementia may also help to identify or rule out other modifiable conditions (e.g., medication side effects, sleep problems, and depression and anxiety) that can cause cognitive changes.

Despite these benefits, there are also concerns that promoting early dementia diagnosis (e.g., through universal screening of all older adults) may lead to increased false positive diagnoses, labeling, and psychological harm. On the one hand, there is a need to address disparities in the health care and outcomes of patients with AD and other dementias, which may be accomplished by promoting individual behaviors and health care practices that increase early detection. On the other hand, an emphasis on early detection could also lead to overdiagnosis and overtreatment of dementia, and the overuse of health care system resources. Given the potential for both benefit and harm from early detection and intervention of dementia, the U.S. Preventive Services Task Force (USPSTF) recently assessed the current evidence on the benefits and harms of universal screening of older adults over age 65 for cognitive impairment, and concluded that

there was insufficient evidence to make a recommendation (Moyer & U. S. Preventive Services Task Force, 2014). The USPSTF found, however, that some screening tools are useful for evaluating patients with dementia. In 2011, the Medicare Annual Wellness Visit (AWV), under the Affordable Care Act, began offering a free assessment of cognitive function. While recommendations have been developed by the Alzheimer's Association to guide primary care physicians in operationalizing this assessment, there is currently no standardized method of carrying out the AWV cognitive evaluation.

### ***Help-Seeking Behavior and Disparities in AD Diagnosis and Treatment***

Missed and delayed diagnoses of dementia are a major public health concern, and have received increasing attention by Alzheimer's research and advocacy communities. While estimates of the prevalence of missed and delayed diagnoses vary across studies, the number appears to be substantial (Bradford, Kunik, Schulz, Williams, & Singh, 2009). A U.S. nationally representative study of people aged 70 or older estimated that around 1.8 million elderly Americans with dementia have not been evaluated for cognitive concerns (Kotagal et al., 2015). The study found that over half (55.2%) of 297 participants who met criteria for dementia had not received a cognitive evaluation by a doctor. A study of Medicare beneficiaries aged 65 or older, enrolled in the National Health and Aging Trends Study, also found that just over half (56%) of 1,038 participants classified as having probable dementia had not been formally diagnosed (Amjad et al., 2016).

Disparities in dementia diagnoses also exist. Older African Americans and Hispanics are not only disproportionately affected by AD, but some evidence suggests that missed and delayed diagnoses are more prevalent among these groups (Alzheimer's Association, 2014; Clark et al., 2005; Fitten, Ortiz, & Ponton, 2001). Clark et al. (2005) found that older adults in some African

American communities may delay consulting a physician about cognitive complaints by as long as seven years. A study of community-dwelling Hispanics age 55 or older showed delays of 3 or more years between presentation of symptoms and diagnosis (Fitten et al., 2001).

One reason for the delays in dementia diagnosis is that many older adults experiencing memory complaints do not seek help by consulting their physicians (Hurt, Burns, Brown, & Barrowclough, 2012; Jorm et al., 2004; Waldorff, Rishoj, & Waldemar, 2008). For instance, in a study of elderly patients at 17 general practices, only 33 (18.6%) of 177 with memory complaints had consulted their physician (Waldorff et al., 2008). Help-seeking is a health-related decision making process, influenced by motivations, beliefs and perceptions, as well as the social environment (Werner, 2004). An extensive literature exists on formal and informal help-seeking across a wide range of health conditions, such as mental health problems (Clement et al., 2015; Dennis & Chung-Lee, 2006; Eisenberg, Hunt, & Speer, 2012; Gulliver, Griffiths, & Christensen, 2012), cancer (Facione, 1993; O'Mahony & Hegarty, 2009), urinary incontinence (Koch, 2006; Shaw, 2001), and hearing loss (Knudsen, Oberg, Nielsen, Naylor, & Kramer, 2010), yet little is known about factors associated with formal help-seeking behavior for memory complaints in older adults.

The small but growing literature on help-seeking for dementia symptoms suggests there may be a number of factors at play, including perceived benefits of and barriers to help-seeking and perceived threat of dementia (Hodgson & Cutler, 2004; Werner, 2003a, 2004), knowledge about dementia (Werner, 2003b), beliefs about causes, severity, and consequences of dementia symptoms (Hamilton-West, Milne, Chenery, & Tilbrook, 2010; Hurt et al., 2012), worry about a family history with dementia (Hurt et al., 2012; Ramakers et al., 2009), and functional decline (Ramakers et al., 2009). Disease stigma and concerns about the potential repercussions of AD

have also been identified as important barriers to seeking help (Devoy & Simpson, 2016; Jones, Chow, & Gatz, 2006; Mukadam, Waugh, Cooper, & Livingston, 2015; Phillipson, Magee, Jones, Reis, & Skaldzien, 2015). Our society views AD as a significant health threat that involves the loss of memory, personal identity, and competency, and carries the potential for social exclusion. Thus, some individuals may be reluctant to seek a diagnosis due to a fear of the social repercussions of the disease, such as shame, rejection, labelling, and discrimination (Devoy & Simpson, 2016; Phillipson et al., 2015). Receiving a dementia diagnosis can be a highly stressful and emotional event (Aminzadeh, Byszewski, Molnar, & Eisner, 2007; Connell, Boise, Stuckey, Holmes, & Hudson, 2004; Holroyd, Turnbull, & Wolf, 2002), and some individuals may be concerned about their ability to cope following a diagnosis, or even lack awareness about the availability of support services and the potential benefits of early diagnosis more generally.

Much of the research conducted to date on help-seeking behavior for memory concerns is based on small convenience samples of older adults with limited racial and ethnic diversity. Few studies have examined predictors of help-seeking behavior in population-based or nationally representative samples. An exploration of demographic, health status, and health care system factors related to help-seeking using population-based data would provide valuable information for addressing disparities in early diagnosis.

### ***The “Worried Well” and AD Overdiagnosis and Overtreatment***

Many older adults, especially those with a family history of the disease, express a high level of perceived AD threat. Adult children of patients who have AD are more likely than those without a family history to engage in symptom-seeking behavior, in which they check for signs of AD or misinterpret a cognitive error as a symptom of the disease (Hodgson, Cutler, & Livingston, 1999). Among those with memory concerns who do consult their doctor, a small but

significant proportion show no signs of cognitive impairment (Alladi, Arnold, Mitchell, Nestor, & Hodges, 2006). Alladi et al. (2006) found that of 124 individuals referred to a memory clinic during a two-year period for the possibility of early dementia, 22 (18%) showed no evidence of cognitive impairment after neuropsychological evaluation. A three-year follow-up study of patients who sought help for memory complaints at an outpatient memory clinic found low conversion rates to mild cognitive impairment (MCI) and dementia, and that memory complaints were significantly associated with psychosocial stress and feelings of anxiety (Elfgren, Gustafson, Vestberg, & Passant, 2010). Thus, psychosocial factors may explain why individuals with no evidence of cognitive impairment may experience subjective memory complaints. These individuals, who have been termed the “worried well,” may have a heightened perceived AD threat, leading them to report memory changes and concerns to a doctor.

Concerns have been raised that, despite progress in early detection of AD, the current emphasis on early diagnosis and screening may result in heightened perceived threat of AD leading to overdiagnosis and overtreatment with adverse consequences for patients and families (Brunet et al., 2012; Le Couteur, Doust, Creasey, & Brayne, 2013). Misdiagnosis of AD can cause individuals and their families undue stress and anxiety, and put individuals at risk for unnecessary and costly treatments and health care actions. To date, very few studies have examined potential factors associated with perceived AD threat. Those that do exist have mainly focused on individuals who may be genetically at risk for AD and/or have been conducted in small convenience samples with limited racial and ethnic diversity (Cutler & Hodgson, 1996; Hodgson & Cutler, 1997, 2003; Roberts & Connell, 2000; Suhr & Kinkela, 2007; Sun, Gao, & Coon, 2015). Gaining a better understanding of potential factors related to perceived AD threat using a nationally representative sample of older adults, with an emphasis on delineating the role



of family experience with AD, would inform large-scale public health efforts aimed at increasing early and accurate diagnosis of AD and the development of decision making models for health care providers to use when assessing patients' memory concerns.

### ***Theoretical Approaches***

Health behavior theories suggest that perceived AD threat is an important predictor of who takes health-related actions such as seeking out a formal cognitive evaluation. For instance, the Health Belief Model (HBM) includes factors such as perceived threat, perceived benefits and barriers, self-efficacy, and cues to action, and has been largely successful in predicting a variety of health-related preventive and screening behaviors (Becker, 1974; Champion & Skinner, 2008; Janz & Becker, 1984). Within the HBM framework, perceived threat has been defined as a combination of perceived susceptibility (i.e., belief about the likelihood of getting the disease) and perceived severity (i.e., perceptions about the seriousness of getting the disease). The Common-Sense Model of Illness Representations (CSM) has also been applied to many health conditions, and includes a variety of cognitive (identify, causes, consequences, and timeframe) and emotional processes that shape personal perceptions of a disease and may predict help-seeking behavior (Leventhal & Nerenz, 1985; Leventhal, Nerenz, & Steele, 1984). According to Leventhal et al. (1984), illness perceptions or representations may be constructed from three forms of information: informal social or formal physician-patient communication, general information from the current culture or environment, and personal (or family) illness experiences.

One study has used social-cognitive theories of health anxiety to guide investigation of predictors of perceived AD threat (Suhr & Kinkela, 2007). These models, proposed by Warwick and Salkovskis (1990) and Williams (2006), consider previous experience with an illness (e.g.,

observing the disease in a family member), as well as individual difference factors such as beliefs about the disease, depression, anxiety, and selective attention to symptoms, to be important factors influencing worry about a disease or perceived threat. The basic assumption of the HBM, CSM and social-cognitive theories of health anxiety is that individuals who perceive that they are susceptible to a disease will be more likely to take action, such as seeking help for their health-related concerns.

### **Dissertation Research Aims and Purpose**

In this dissertation, I examine the influence of a variety of factors on perceived AD threat and help-seeking behavior among older adults with memory complaints (see Figure 1-1). Help-seeking in this context means the act of seeking medical help from a health care professional. This body of work is exploratory in nature, but also informed by evidence from the help-seeking literature, and by HBM, CSM, and health anxiety theoretical frameworks. In particular, my research examines potential factors associated with perceived AD threat and considers experiential factors (e.g., family history), disease knowledge and beliefs, as well as psychosocial (e.g., symptoms of depression) and cognitive factors (memory complaints and impairment). This research also addresses gaps in the literature concerning how health care access factors, such as insurance coverage, cost, and access to a health care provider, may affect help-seeking behavior among older adults with memory complaints. The dissertation consists of three separate but related papers:

Chapter 2 is a systematic review of the empirical literature on formal help-seeking behavior for dementia concerns. This review addresses the following question: What factors have been identified as facilitators or barriers to older adults, or their caregivers, seeking formal

help for SMCs or concerns about developing dementia? Empirical studies are critically analyzed to identify strengths, limitations, and gaps in the literature.

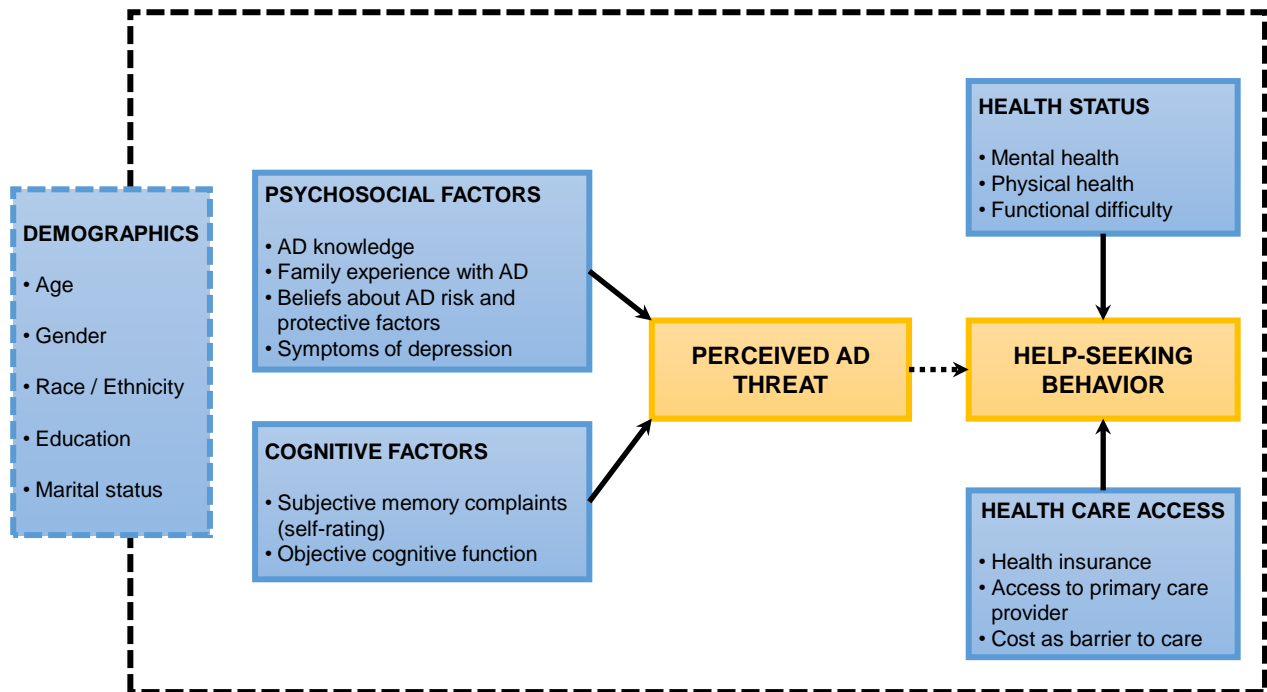
Chapter 3 focuses on examining psychosocial and cognitive predictors of perceived AD threat using U.S. nationally representative data from the U-M Health and Retirement Study. Two questions are addressed: 1) What are the significant psychosocial and cognitive factors associated with perceived AD threat?, and 2) Does family experience with AD moderate the relationship between cognitive factors and perceived threat? Respondents were 1,641 adults aged  $\geq 50$  who completed a brief supplementary survey module, included in the Health and Retirement Study, focused on knowledge and beliefs about AD.

Chapter 4 uses population-based data from the Behavioral Risk Factor Surveillance System to assess demographic, health care access, and health status predictors of help-seeking behavior among older adults with subjective memory complaints. This paper addresses the following question: what is the association among demographic factors (i.e., age, gender, race, education, marital status, geographic region), health care access (i.e., health care coverage, cost and services), health status (i.e., functional difficulty, mental and physical health), and help-seeking behavior for memory complaints? In 2011, 21 of the 50 states that conducted the BRFSS survey included a 10-question cognitive impairment module in their surveys. Respondents were 6,807 older adult module completers aged  $\geq 60$  who reported confusion or memory loss that is happening more often or getting worse.

The overall purpose of this research is to inform policies and interventions aimed at increasing early and accurate diagnosis of dementia, and to gain insight into factors related to perceived AD threat and help-seeking behavior that may help health care professionals when evaluating patients' memory complaints. This research is intended to inform the development of

decision making models around the following two issues: 1) a lack of formal help-seeking leading to greater disparities and under-treatment, and 2) heightened personal risk for AD leading to overdiagnosis and overtreatment.

**Figure 1-1:** Conceptual Model of Perceived AD Threat and Help-Seeking Behavior



## References

- Alladi, S., Arnold, R., Mitchell, J., Nestor, P. J., & Hodges, J. R. (2006). Mild cognitive impairment: applicability of research criteria in a memory clinic and characterization of cognitive profile. *Psychol Med*, *36*(4), 507-515.
- Alzheimer's Association. (2014). 2014 Alzheimer's Disease Facts and Figures. Retrieved from [http://www.alz.org/downloads/Facts\\_Figures\\_2014.pdf](http://www.alz.org/downloads/Facts_Figures_2014.pdf)
- Alzheimer's Association. (2016). 2016 Alzheimer's Disease Facts and Figures. Retrieved from [http://www.alz.org/documents\\_custom/2016-facts-and-figures.pdf](http://www.alz.org/documents_custom/2016-facts-and-figures.pdf)
- Alzheimer's Association, & Centers for Disease Control and Prevention. (2013). *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*. Retrieved from <http://www.alz.org/publichealth/downloads/2013-RoadMap.pdf>
- Aminzadeh, F., Byszewski, A., Molnar, F. J., & Eisner, M. (2007). Emotional impact of dementia diagnosis: exploring persons with dementia and caregivers' perspectives. *Aging Ment Health*, *11*(3), 281-290.
- Amjad, H., Roth, D. L., Samus, Q. M., Yasar, S., & Wolff, J. L. (2016). Potentially Unsafe Activities and Living Conditions of Older Adults with Dementia. *J Am Geriatr Soc*, *64*(6), 1223-1232.
- Becker, M. H. (1974). The Health Belief Model and Personal Health Behavior. *Health Education Monographs*, *2*, 324-473.
- Bradford, A., Kunik, M. E., Schulz, P., Williams, S. P., & Singh, H. (2009). Missed and delayed diagnosis of dementia in primary care: prevalence and contributing factors. *Alzheimer Dis Assoc Disord*, *23*(4), 306-314.
- Brookmeyer, R., Evans, D. A., Hebert, L., Langa, K. M., Heeringa, S. G., Plassman, B. L., & Kukull, W. A. (2011). National estimates of the prevalence of Alzheimer's disease in the United States. *Alzheimers Dement*, *7*(1), 61-73.
- Brunet, M. D., McCartney, M., Heath, I., Tomlinson, J., Gordon, P., Cosgrove, J., . . . Bhattia, N. (2012). There is no evidence base for proposed dementia screening. *BMJ*, *345*, e8588.
- Budd, D., Burns, L. C., Guo, Z., L'Italien, G., & Lapuerta, P. (2011). Impact of early intervention and disease modification in patients with predementia Alzheimer's disease: a Markov model simulation. *Clinicoecon Outcomes Res*, *3*, 189-195.
- Champion, V. L., & Skinner, C. S. (2008). The Health Belief Model. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health Behavior and Health Education* (pp. 45-62). San Francisco, CA.
- Clark, P. C., Kutner, N. G., Goldstein, F. C., Peterson-Hazen, S., Garner, V., Zhang, R., & Bowles, T. (2005). Impediments to timely diagnosis of Alzheimer's disease in African Americans. *J Am Geriatr Soc*, *53*(11), 2012-2017.
- Clement, S., Schauman, O., Graham, T., Maggioni, F., Evans-Lacko, S., Bezborodovs, N., . . . Thornicroft, G. (2015). What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. *Psychol Med*, *45*(1), 11-27.
- Connell, C. M., Boise, L., Stuckey, J. C., Holmes, S. B., & Hudson, M. L. (2004). Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians. *Gerontologist*, *44*(4), 500-507.
- Cutler, S. J., & Hodgson, L. G. (1996). Anticipatory dementia: a link between memory appraisals and concerns about developing Alzheimer's disease. *Gerontologist*, *36*(5), 657-664.

- de Vugt, M. E., & Verhey, F. R. (2013). The impact of early dementia diagnosis and intervention on informal caregivers. *Prog Neurobiol*, *110*, 54-62.
- Dennis, C. L., & Chung-Lee, L. (2006). Postpartum depression help-seeking barriers and maternal treatment preferences: a qualitative systematic review. *Birth*, *33*(4), 323-331.
- Devoy, S., & Simpson, E. E. (2016). Help-seeking intentions for early dementia diagnosis in a sample of Irish adults. *Aging Ment Health*, 1-9.
- Eisenberg, D., Hunt, J., & Speer, N. (2012). Help seeking for mental health on college campuses: review of evidence and next steps for research and practice. *Harv Rev Psychiatry*, *20*(4), 222-232.
- Elfgrén, C., Gustafson, L., Vestberg, S., & Passant, U. (2010). Subjective memory complaints, neuropsychological performance and psychiatric variables in memory clinic attendees: a 3-year follow-up study. *Arch Gerontol Geriatr*, *51*(3), e110-114.
- Facione, N. C. (1993). Delay versus help seeking for breast cancer symptoms: a critical review of the literature on patient and provider delay. *Soc Sci Med*, *36*(12), 1521-1534.
- Fitten, L. J., Ortiz, F., & Ponton, M. (2001). Frequency of Alzheimer's disease and other dementias in a community outreach sample of Hispanics. *J Am Geriatr Soc*, *49*(10), 1301-1308.
- Gulliver, A., Griffiths, K. M., & Christensen, H. (2012). Barriers and facilitators to mental health help-seeking for young elite athletes: a qualitative study. *BMC Psychiatry*, *12*, 157.
- Hamilton-West, K. E., Milne, A. J., Chenery, A., & Tilbrook, C. (2010). Help-seeking in relation to signs of dementia: a pilot study to evaluate the utility of the common-sense model of illness representations. *Psychol Health Med*, *15*(5), 540-549.
- Hebert, L. E., Weuve, J., Scherr, P. A., & Evans, D. A. (2013). Alzheimer disease in the United States (2010-2050) estimated using the 2010 census. *Neurology*, *80*(19), 1778-1783.
- Hodgson, L. G., & Cutler, S. J. (1997). Anticipatory dementia and well-being. *Am J Alzheimers Dis Other Demen*, *12*, 62-66.
- Hodgson, L. G., & Cutler, S. J. (2003). Looking for signs of Alzheimer's disease. *Int J Aging Hum Dev*, *56*(4), 323-343.
- Hodgson, L. G., & Cutler, S. J. (2004). Help Seeking for Personal Concerns About Developing Alzheimer's Disease. *J Appl Gerontol*, *23*, 385-410.
- Hodgson, L. G., Cutler, S. J., & Livingston, K. (1999). Alzheimer's disease and symptom-seeking. *Am J Alzheimers Dis Other Demen*, *14*(6), 364-374.
- Holroyd, S., Turnbull, Q., & Wolf, A. M. (2002). What are patients and their families told about the diagnosis of dementia? Results of a family survey. *Int J Geriatr Psychiatry*, *17*(3), 218-221.
- Hurt, C. S., Burns, A., Brown, R. G., & Barrowclough, C. (2012). Why don't older adults with subjective memory complaints seek help? *Int J Geriatr Psychiatry*, *27*(4), 394-400.
- Janz, N. K., & Becker, M. H. (1984). The Health Belief Model: a decade later. *Health Educ Q*, *11*(1), 1-47.
- Jones, R. S., Chow, T. W., & Gatz, M. (2006). Asian Americans and Alzheimer's disease: Assimilation, culture, and beliefs. *Journal of Aging Studies*, *20*(1), 11-25.
- Jorm, A. F., Butterworth, P., Anstey, K. J., Christensen, H., Easteal, S., Maller, J., . . . Sachdev, P. (2004). Memory complaints in a community sample aged 60-64 years: associations with cognitive functioning, psychiatric symptoms, medical conditions, APOE genotype, hippocampus and amygdala volumes, and white-matter hyperintensities. *Psychol Med*, *34*(8), 1495-1506.

- Knudsen, L. V., Oberg, M., Nielsen, C., Naylor, G., & Kramer, S. E. (2010). Factors influencing help seeking, hearing aid uptake, hearing aid use and satisfaction with hearing aids: a review of the literature. *Trends Amplif*, *14*(3), 127-154.
- Koch, L. H. (2006). Help-seeking behaviors of women with urinary incontinence: an integrative literature review. *J Midwifery Womens Health*, *51*(6), e39-44.
- Kotagal, V., Langa, K. M., Plassman, B. L., Fisher, G. G., Giordani, B. J., Wallace, R. B., . . . Foster, N. L. (2015). Factors associated with cognitive evaluations in the United States. *Neurology*, *84*(1), 64-71.
- Le Couteur, D. G., Doust, J., Creasey, H., & Brayne, C. (2013). Political drive to screen for pre-dementia: not evidence based and ignores the harms of diagnosis. *BMJ*, *347*, f5125.
- Leventhal, H., & Nerenz, D. (1985). The assessment of illness cognition. In P. Korely (Ed.), *Measurement Strategies in Health Psychology* (pp. 517-554). New York: Wiley.
- Leventhal, H., Nerenz, D. R., & Steele, D. J. (1984). Illness representations and coping with health threats. In A. Baum, S. E. Taylor, & J. E. Singer (Eds.), *A Handbook of Psychology and Health, Volume IV: Social Psychological Aspects of Health* (pp. 219-252). New Jersey: Erlbaum.
- Moyer, V. A., & U. S. Preventive Services Task Force. (2014). Screening for cognitive impairment in older adults: U.S. Preventive Services Task Force recommendation statement. *Ann Intern Med*, *160*(11), 791-797.
- Mukadam, N., Waugh, A., Cooper, C., & Livingston, G. (2015). What would encourage help-seeking for memory problems among UK-based South Asians? A qualitative study. *BMJ Open*, *5*(9), e007990.
- National Institute on Aging. (2014). Alzheimer's Disease Medications Fact Sheet. Retrieved from <http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-medications-fact-sheet>
- O'Mahony, M., & Hegarty, J. (2009). Help seeking for cancer symptoms: a review of the literature. *Oncol Nurs Forum*, *36*(4), E178-184.
- Phillipson, L., Magee, C., Jones, S., Reis, S., & Skaldzien, E. (2015). Dementia attitudes and help-seeking intentions: an investigation of responses to two scenarios of an experience of the early signs of dementia. *Aging Ment Health*, *19*(11), 968-977.
- Ramakers, I. H., Visser, P. J., Bittermann, A. J., Ponds, R. W., van Boxtel, M. P., & Verhey, F. R. (2009). Characteristics of help-seeking behaviour in subjects with subjective memory complaints at a memory clinic: a case-control study. *Int J Geriatr Psychiatry*, *24*(2), 190-196.
- Relkin, N. (2000). Screening and early diagnosis of dementia. *Am J Manag Care*, *6*(22 Suppl), S1111-1118; discussion S1119-1124.
- Roberts, J. S., & Connell, C. M. (2000). Illness representations among first-degree relatives of people with Alzheimer disease. *Alzheimer Dis Assoc Disord*, *14*(3), 129-136, Discussion 127-128.
- Shaw, C. (2001). A review of the psychosocial predictors of help-seeking behaviour and impact on quality of life in people with urinary incontinence. *J Clin Nurs*, *10*(1), 15-24.
- Suhr, J. A., & Kinkela, J. H. (2007). Perceived threat of Alzheimer disease (AD): the role of personal experience with AD. *Alzheimer Dis Assoc Disord*, *21*(3), 225-231.
- Sun, F., Gao, X., & Coon, D. W. (2015). Perceived threat of Alzheimer's disease among chinese american older adults: the role of Alzheimer's disease literacy. *J Gerontol B Psychol Sci Soc Sci*, *70*(2), 247-257.

- U.S. Department of Health and Human Services. (2016). National Plan to Address Alzheimer's Disease: 2016 Update. Retrieved from <https://aspe.hhs.gov/sites/default/files/pdf/205581/NatlPlan2016.pdf>
- Waldorff, F. B., Rishoj, S., & Waldemar, G. (2008). If you don't ask (about memory), they probably won't tell. *J Fam Pract*, 57(1), 41-44.
- Warwick, H. M. C., & Salkovskis, P. M. (1990). Hypochondriasis. *Behav Res Ther*, 28, 105-117.
- Weimer, D. L., & Sager, M. A. (2009). Early identification and treatment of Alzheimer's disease: social and fiscal outcomes. *Alzheimers Dement*, 5(3), 215-226.
- Werner, P. (2003a). Factors influencing intentions to seek a cognitive status examination: a study based on the Health Belief Model. *Int J Geriatr Psychiatry*, 18(9), 787-794.
- Werner, P. (2003b). Knowledge about symptoms of Alzheimer's disease: Correlates and relationships to help-seeking behavior. *International Journal of Geriatric Psychiatry*, 18, 1029-1036.
- Werner, P. (2004). Beliefs About Memory Problems and Help Seeking in Elderly Persons. *Clinical Gerontologist*, 27(4), 19-30.
- Williams, P. G. (2006). The psychopathology of self-assessed health: A cognitive approach to health anxiety and hypochondriasis. *Cogn Ther Res*, 28, 629-644.
- World Health Organization. (2012). Dementia: A public health priority. Retrieved from [http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1)



## **CHAPTER 2**

### **Factors Influencing Help-Seeking among Older Adults with Dementia Concerns: A Systematic Review**

#### **Introduction**

As the older population in the U.S. continues to grow, the number of Alzheimer's disease (AD) cases is projected to rise dramatically in the coming years (Hebert, Weuve, Scherr, & Evans, 2013). AD takes a substantial mental, physical, and financial toll on patients, caregivers, and families. The total annual cost of health care, long-term care, and hospice for people with AD and other dementias is currently estimated at around \$236 billion, and may reach more than \$1 trillion by 2050 (Alzheimer's Association, 2016).

Given the health and economic burden of AD, and the projected rise in cases, there is a growing need to raise awareness about AD, facilitate early help-seeking, and improve access to early diagnosis and intervention for affected patients and their caregivers. To this end, many agencies and organizations, including local and state health departments, as well as the Centers for Disease Control and Prevention, the Alzheimer's Association, and the World Health Organization, have taken steps to promote early detection and diagnosis of dementia as a public health priority (Alzheimer's Association & Centers for Disease Control and Prevention, 2013; World Health Organization, 2012). Early detection and diagnosis may offer several benefits to affected persons and their families, including prompting time for long-term planning activities such as making living arrangements and discussing financial and legal affairs. An early diagnosis can also improve timely access to treatments, care and support services (de Vugt & Verhey,

2013; Relkin, 2000; World Health Organization, 2012), and may even lessen symptom severity and enhance quality of life when pharmaceutical treatments are started early (National Institute on Aging, 2014). The societal costs associated with the disease, such as hospitalizations and institutional placement, may also be reduced with earlier diagnosis (Relkin, 2000; Weimer & Sager, 2009).

Despite the potential benefits of early diagnosis, many older adults with dementia do not receive a timely diagnosis. A recent nationally representative study of persons age 70 or older estimated that around 1.8 million elderly Americans with dementia have not been evaluated for cognitive concerns (Kotagal et al., 2015). The study found that over half (55.2%) of 297 participants who met criteria for dementia had not received a cognitive evaluation by a doctor. In another study of elderly patients at 17 general practices, only 33 (18.6%) of 177 with memory complaints had consulted their physician (Waldorff, Rishoj, & Waldemar, 2008). Disparities in dementia diagnoses also persist with missed and delayed diagnoses more prevalent among older African Americans and Hispanics (Alzheimer's Association, 2014; Clark et al., 2005; Fitten, Ortiz, & Ponton, 2001). Clark et al. (2005) found that older adults in some African American communities may delay consulting a physician about cognitive complaints by as long as seven years. A study of community-dwelling Hispanics age 55 or older showed delays of 3 or more years between presentation of symptoms and diagnosis (Fitten et al., 2001). A delay in this case may mean either that an individual does not seek to obtain a diagnosis or that there are barriers in the process that preclude a timely diagnosis.

One reason for a lack of timely diagnosis is that many older adults experiencing cognitive problems do not discuss their concerns with a doctor. The term “help seeking” has been used in the social psychological and medical literature to refer to the process of communicating concerns

to others in order to obtain assistance (Rickwood & Thomas, 2012). This assistance could come in the form of understanding, information, treatment or support for a problem or distressing situation. Help seeking has been conceptualized as part of the illness behavior process, and as an active or problem-focused form of coping (Mechanic, 1982; Rickwood & Thomas, 2012). The literature distinguishes between formal and informal help-seeking. Formal help-seeking is assistance from professional sources for advice, treatment or support, while informal help-seeking is assistance from family, friends and neighbors (Rickwood & Thomas, 2012). While factors influencing both formal and informal help-seeking across a wide range of health conditions, such as mental health problems (Clement et al., 2015; Dennis & Chung-Lee, 2006; Eisenberg, Hunt, & Speer, 2012; Gulliver, Griffiths, & Christensen, 2012), cancer (Facione, 1993; O'Mahony & Hegarty, 2009), urinary incontinence (Koch, 2006; Shaw, 2001), and hearing loss (Knudsen, Oberg, Nielsen, Naylor, & Kramer, 2010), have been examined, little is known about formal help-seeking behavior for symptoms of or concerns about dementia among older adults.

The purpose of this review is to critically evaluate the empirical literature focused on formal help-seeking to obtain a diagnosis or treatment from a health care provider, either by individuals experiencing subjective memory complaints (SMCs) or dementia concerns themselves or by a caregiver. SMCs are a common concern among older adults and viewed as an early indicator of cognitive decline. While other review articles in this area have focused either more broadly on both informal and formal help-seeking across the disease course (Werner, Goldstein, Karpas, Chan, & Lai, 2014), or more specifically on help-seeking among certain racial/ethnic groups or populations (Daker-White, Beattie, Gilliard, & Means, 2002; Naaheed Mukadam, Cooper, & Livingston, 2011), we were interested in identifying factors that influence

initial diagnostic assessment or treatment. Our review, therefore, addressed the following question: What factors have been identified as facilitators or barriers to older adults, or their caregivers, seeking formal help for SMCs or concerns about developing dementia? A critical analysis of identified empirical studies was conducted to identify strengths, limitations, and gaps in the literature.

## **Methods**

### ***Search Strategy***

A web-based search was conducted in July and August 2015 for empirical literature on the topic of help-seeking for SMCs or concerns about dementia among older adults. An updated search was conducted in October 2016 to retrieve any recently published articles since the prior search. Several online databases were used to provide an exhaustive summary of current literature: PubMed, PsycINFO, Google Scholar, Science Direct, and Web of Science. We adopted a key word search strategy similar to one used for another systematic review (Werner, Goldstein, et al., 2014). We chose to focus on the term “help-seeking” for two reasons: 1) it has been widely used in the medical and mental health literature to refer to the process of seeking a diagnosis or treatment, and 2) doing so effectively narrowed the search results to relevant articles. The key words used were: i) help seeking AND Alzheimer OR ii) help seeking AND dementia OR iii) help seeking AND subjective memory complaints OR iv) help seeking AND cognitive impairment. These searches were supplemented by manually checking reference lists of obtained articles, as well as conducting online searches of journals focused on aging research (e.g., Alzheimer’s Disease and Associated Disorders, International Journal of Geriatric Psychiatry, etc.).

### ***Inclusion Criteria***

Several inclusion criteria were established. All studies included in the review were empirical, published in English in peer-reviewed journals, and specific to the topic of formal help-seeking for SMCs or concerns about developing dementia. Studies that examined both formal and informal help-seeking were included. Review articles, abstracts, dissertations, letters to the editor, books, conference proceedings, reports, and intervention/program evaluation studies were excluded, although identified review articles were collected and used for manual reference searches. During the preliminary assessment, all titles, key words, and abstracts were reviewed to identify relevant empirical articles. Articles that met inclusion criteria after initial review were compiled in an EndNote database and later scanned for duplicates. The remaining articles were then read in full and further assessed to ensure that the inclusion criteria were satisfied.

### **Results**

The final sample consists of 61 total articles (Table 2-1). The database search conducted in July and August 2015 yielded 64 distinct articles (after duplicates were removed) that met inclusion criteria based on preliminary assessment of titles, key words, and abstracts. Of these, 18 articles were excluded after further reading and assessment as 16 were not relevant to the topic (i.e., focused on informal support or information seeking or on mental health help-seeking more generally) and 2 were not empirical. Manual searches yielded 8 additional articles included in the final sample. An updated database search in October 2016 yielded 7 newly published articles, which were included in the final sample. The sample selection process is detailed in Figure 2-1.

There was some overlap between the sample of articles identified for this study and that obtained by Werner, Goldstein, et al. (2014). Specifically, 27 of the 61 articles were also included in their study's final sample. This was expected given that we implemented a similar keyword search strategy. Differences in obtained samples may be explained by our study's narrower focus on "formal" help-seeking to obtain a diagnosis or treatment, our use of additional databases to conduct literature searches, and the later time period in which our searches were completed. Of the 34 newly sampled articles, 22 (65%) were published between 2013 and 2016.

### ***Background of Studies***

#### *Time Period and Location*

Background information on the sampled studies is summarized in Table 2-2. Publications in this area substantially increased from only 5 (8.2%) prior to 2000, to 21 (34.4%) between 2000 and 2009. Publications have also risen in the last six years between 2010 and 2016, constituting 57.4% of the sample. The studies originated in 10 different countries, with most undertaken in the U.S. (37.7%), U.K. (24.6%), Israel (13.1%), and Canada (9.8%). While over one-third of the sampled studies took place in the U.S., the majority of studies (62.3%) were conducted in other countries.

#### *Sample and Methods*

Studies were nearly evenly split between those taking a quantitative (44.3%) approach to data analysis and those using a qualitative (42.6%) or mixed methods (13.1%) approach. Almost all were cross-sectional and based on convenience sampling. One study was longitudinal (Morgan et al., 2014), and 5 used random sampling methods (Blay, Furtado, & Peluso, 2008; Galvin, Fu, Nguyen, Glasheen, & Scharff, 2008; Juarez-Cedillo, Jarillo-Soto, & Rosas-Carrasco, 2014; Low, Anstey, Lackersteen, & Camit, 2011; Ploeg et al., 2009). There were two nationally

representative studies: one was a U.S. nationally representative community-based cohort study (Kotagal et al., 2015), and the other used a nationally representative sample of Israeli family physicians (Werner, 2007). Three others used population-based samples of Sao Paulo household residents (Blay et al., 2008), community-dwelling older adults in Missouri (Galvin et al., 2008), and adult residents in Hamilton, Ontario (Ploeg et al., 2009). A comparison or control group was included in 11 studies.

Sample size varied across studies. Around half ( $n = 33$ ) had relatively small sample sizes of  $<100$ , with 9 studies having very small samples of  $<20$ . Three studies were based on samples over 1,000. Many studies ( $n = 31$ ) recruited and interviewed caregivers and/or family members of older adults with SMCs, cognitive impairment, or dementia. Older adults were sampled in 26 studies, 5 of which were conducted among persons with SMCs, 3 among persons with cognitive impairment or MCI, 11 among persons with a dementia diagnosis, and 7 among the lay public. Six studies recruited physicians, health care or community workers. Twelve studies used mixed samples of caregivers, older adults and/or health care/community workers. Vignettes depicting persons with symptoms of dementia were used in 11 studies, 2 of which had less conventional study samples of undergraduate psychology students and community residents awaiting jury service. Nearly all studies ( $n=55$ , 90.2%) had a majority of female participants across all populations sampled (2 studies did not include information on gender). Racial/ethnic information on sampled participants was provided in 33 (54.1%) studies. Of these, only 19 offered cross-group comparisons or focused exclusively on one or more racial/ethnic minority groups.

### *Theoretical Approach*

The vast majority of the sampled studies did not use a theoretical model or framework (72.1%). Of those that did, the Health Belief Model was the most commonly used (6 studies),

followed by the Common-Sense Model of Illness Representations (3 studies), the Theory of Planned Behavior/Theory of Reasoned Action (3 studies), and Levkoff's Help-Seeking Model (2 studies). Other theoretical models used were Anderson's Behavioral Model of Health Services Use, the Cognitive Impairment Response Model, and Parson's Model of the Sick Role. Two studies integrated multiple theoretical approaches.

### *Measures of Formal Help-Seeking*

Nearly all studies relied on investigator generated self-report questions on formal help-seeking. The exceptions to this were four case-control studies that specifically recruited and compared formal help-seekers and non-formal help-seekers (Begum et al., 2013; Hurt, Burns, Brown, & Barrowclough, 2012; Pires et al., 2012; Ramakers et al., 2009).

A variety of self-report questions were constructed across studies, such as "Have you had your relative's memory checked by a doctor?" (Casado, Lee, Hong, & Hong, 2015), "Have you or another family member discussed these difficulties with his/her primary care physician?" (Hinton, Chambers, Velásquez, Gonzalez, & Haan, 2006), and "Has [name] ever seen a doctor for any concerns with her/his memory or thinking?" (Kotagal et al., 2015). One study asked cognitively impaired and non-impaired elderly participants whether they had visited a health professional (Frank, German, Burns, & Johnson, 1988). Another presented older adult patients with a list of symptoms and asked if they had sought help from medical services for these symptoms from a GP, a consultant team or both (Begum, Morgan, Chiu, Tylee, & Stewart, 2012). Several studies presented participants with a list of sources of help (formal, or both formal and informal) and/or options for treatment or intervention, and asked them to rate them or choose between them (Blay et al., 2008; Hodgson & Cutler, 2004; Low et al., 2011; Ploeg et al., 2009; Werner, 2003b, 2004b; Werner, Heinik, Giveon, Segel-Karpas, & Kitai, 2014). Three studies



asked physicians to rate the extent to which they would recommend a number of possible sources of help and/or treatment options (Werner, 2007; Werner, Heinik, et al., 2014; Werner, Heinik, & Kitai, 2013).

Intention to seek help was often used as a proxy for actual help-seeking behavior. For instance, studies asked about intention to seek help for memory problems or early signs of dementia (Devoy & Simpson, 2016; Hailstone, Mukadam, Owen, Cooper, & Livingston, 2016; Phillipson, Magee, Jones, Reis, & Skaldzien, 2015; Werner, 2004a), intention to seek a cognitive status examination during the next year or during the next five years (Werner & Heinik, 2004), intention to pursue follow-up diagnostic evaluation following positive screening for memory problems (Williams, Tappen, Rosselli, Keane, & Newlin, 2010), and intention to screen for Alzheimer's disease (Galvin et al., 2008). Intention was also used as a proxy for help-seeking behavior in several studies using vignette methodology (Berwald, Roche, Adelman, Mukadam, & Livingston, 2016; Hamilton-West, Milne, Chenery, & Tilbrook, 2010; Qualls et al., 2015; Watari & Gatz, 2004; Werner, 2003a, 2003b, 2004b).

A few studies focused help-seeking questions on determining potential benefits, barriers or enablers to obtaining a diagnosis or medical evaluation (Connell, Roberts, McLaughlin, & Carpenter, 2009; Haralambous et al., 2014; N. Mukadam, Waugh, Cooper, & Livingston, 2015; Peterson, Hahn, Lee, Madison, & Atri, 2016; Streams, Wackerbarth, & Maxwell, 2003; Wackerbarth & Johnson, 2002; Watari & Gatz, 2004; Werner, 2004a). Some studies obtained specific information from family members about the dementia diagnosis, such as the dates when symptoms were noticed, when a physician was consulted, when the diagnosis was made, and why there might have been a delay in diagnosis (Boise, Morgan, Kaye, & Camicioli, 1999; Feldman, Wilcock, Thuné-Boyle, & Iliffe, 2015; Schrauf & Iris, 2012; Zhao et al., 2015).

Several qualitative studies focused on understanding individuals' pathways or personal experiences in seeking formal help by using open-ended questions and semi-structured interview techniques (Braun, Takamura, & Mougeot, 1996; Campbell et al., 2016; Connell, Boise, Stuckey, Holmes, & Hudson, 2004; Garcia et al., 2014; Hinton, Franz, & Friend, 2004; Hodgson, Cutler, & Livingston, 1999; Hughes, Tyler, Danner, & Carter, 2009; Innes, Szymczynska, & Stark, 2014; Jones, Chow, & Gatz, 2006; Juarez-Cedillo et al., 2014; Koehn et al., 2012; Leung et al., 2011; Levkoff, Levy, & Weitzman, 1999; McCleary et al., 2013; Millard & Baune, 2009; Morgan et al., 2014; Morhardt, Pereyra, & Iris, 2010; N. Mukadam, Cooper, Basit, & Livingston, 2011; Peterson et al., 2016; Samsi et al., 2014). For example, one study asked participants to describe what happened at various stages of their journey in deciding to seek medical help (Chrisp, Tabberer, & Thomas, 2013). Another inquired about participants' experiences of consulting their GP about memory problems, as well as their experiences at memory clinics (Dean, Jenkinson, Wilcock, & Walker, 2014).

### *Factors Influencing Formal Help-Seeking*

The sampled studies uncovered a number of factors related to formal help-seeking variables and outcomes. The identified factors can be further grouped into five domains or social determinants of health: 1) sociodemographic characteristics, 2) knowledge, beliefs and personal experiences, 3) psychosocial factors, 4) cognitive and disease-related factors, and 5) health care policies, access and services. These domains and the factors that comprise them are interrelated and interdependent. This classification reflects a variety of behavioral theories and socio-ecological approaches to health and disease, whereby health behaviors and outcomes are shaped by the interaction between factors related to the disease, individual characteristics and beliefs, and social context and systems (Andersen & Newman, 1973; Becker, 1974; Leventhal, Nerenz,

& Steele, 1984; McLeroy, Bibeau, Steckler, & Glanz, 1988). The following sections describe findings from the full sample of articles (quantitative, qualitative, and mixed methods studies) by domain. Table 2-3 provides a list of domains and categories with examples of key study findings.

### 1. Sociodemographic characteristics

The sampled articles identify a range of sociodemographic factors that may directly or indirectly relate to formal help-seeking behavior, including age, gender, racial/ethnic background, marital status, income, and education level. Younger age has been associated with greater perceived benefits of seeking help (Werner, 2003a), while older age has been associated with lower knowledge levels about AD (Werner, 2003b). In a vignette depicting symptoms of AD, Qualls et al. (2015) found a significant positive association between age and symptom identification, and a negative association between age and intent to seek a medical evaluation. Gender has been identified as a factor related to help-seeking behavior, as women may be more likely to consult with others about their AD concerns than men (Hodgson et al., 1999). Female gender has also been associated with increased AD knowledge (Hodgson & Cutler, 2004), which may play a role in help-seeking. Several studies included in this review suggest that there may be racial/ethnic differences in perceived benefits and barriers to obtaining a diagnosis (Connell et al., 2009), symptom attribution or appraisal (Levkoff et al., 1999), and general patterns of formal help-seeking behavior (Hinton et al., 2006; Hinton et al., 2004; Low et al., 2011; Schrauf & Iris, 2012; Williams et al., 2010). For instance, in a study of family members of people with AD, African Americans endorsed certain access-related barriers to getting a diagnosis of AD (e.g., “there are so few physicians trained to diagnose dementia in my local area,” “the process was so expensive,” and “our health insurance did not cover the process”) more frequently than Whites

(Connell et al., 2009). Some racial/ethnic minority groups may also encounter language barriers in health care settings that could deter help-seeking (Braun et al., 1996; Casado et al., 2015).

In a U.S. nationally representative study, being married was found to be a significant predictor of receiving a clinical evaluation for cognitive impairment (Kotagal et al., 2015). Older adults with higher levels of education are also likely to seek out more information sources about AD than those with lower levels of education (Hodgson & Cutler, 2004). Nonetheless, one study conducted in China found an association between higher education levels and an increased delay in help-seeking (Zhao et al., 2015). In a study of first degree relatives of persons with AD, Werner and Heinik (2004) found that higher income was associated with lower intention to seek a cognitive status examination.

## 2. Knowledge, Beliefs, and Personal Experiences

Knowledge about symptoms of dementia. Knowledge about symptoms of AD or dementia was implicated in help-seeking behavior in a number of studies (Boise et al., 1999; Devoy & Simpson, 2016; Galvin et al., 2008; Garcia et al., 2014; Hodgson & Cutler, 2004; Juarez-Cedillo et al., 2014; Qualls et al., 2015; Watari & Gatz, 2004; Werner, 2003b; Werner & Heinik, 2004). For instance, older adults with more AD knowledge report more help-seeking from formal networks (Hodgson & Cutler, 2004), more willingness to be tested for cognitive problems (Galvin et al., 2008), and more intention to seek help from professional sources (Werner, 2003b). AD knowledge may also increase the likelihood that symptoms of AD are recognized and experienced as salient (Qualls et al., 2015), indirectly affecting help-seeking. Lack of knowledge or awareness about dementia symptoms or memory concerns was also identified as a factor deterring help-seeking in two studies (Boise et al., 1999; Garcia et al., 2014).

Personal experience with dementia. Personal experience with dementia, including having a close relative with the disease, may influence help-seeking behavior (Hodgson & Cutler, 2004; Hurt et al., 2012; Ramakers et al., 2009; Zhao et al., 2015). In a study of older adults, the most important predictor of help-seeking for concerns of developing AD was that of personal AD experience (Hodgson & Cutler, 2004). Respondents who reported a parent with AD were more likely to seek out informal and formal sources of help than those who did not report a parent with AD. In another study, Ramakers et al. (2009) found that older adults with SMCs who had sought help at a memory clinic were more likely to be worried about a family history of dementia compared to older adults with SMCs who had not sought help. Conversely, one study conducted in China found the opposite—that having a family history of dementia was associated with an increased delay in help-seeking (Zhao et al., 2015).

Perceived benefits and barriers to obtaining a diagnosis. Several studies explored perceptions about benefits and barriers to obtaining a memory assessment or diagnosis (Galvin et al., 2008; Hailstone et al., 2016; N. Mukadam et al., 2015; Wackerbarth & Johnson, 2002; Watari & Gatz, 2004; Werner, 2004a; Werner & Heinik, 2004). In a study of family members of people with AD, three benefits were rated as extremely important: learning what was wrong with their family member, the ability to make future plans, and obtaining information about the disease (Connell et al., 2009). Two of the most frequently endorsed barriers to seeking a diagnosis were lack of a cure for AD and the belief that little can be done for someone with AD (Connell et al., 2009). In a study of family caregivers in five limited English proficiency communities (Arab, Assyrian, Bosnian, Hindi, and Urdu), those who sought a formal evaluation for memory problems did so because they wanted treatment to slow the disease progression, they wanted to get help for bothersome symptoms, and/or they were hoping to find a cure (Morhardt

et al., 2010). Wackerbarth and Johnson (2002) found similar perceived benefits expressed by family caregivers, such as making the most out of the present, confirmation of a medical condition, access to treatment, knowing what to expect in the future, and help preparing for the role of caregiving. Many of the frequently endorsed perceived barriers by respondents in this study were emotional and pragmatic, including: having a hard time accepting the family member's decline, worry about the impact of a diagnosis on their own life and that of their family member, and worry about financial cost of a diagnostic assessment. In a study of community-dwelling older adults, Werner (2003a) found that intention to seek a cognitive status exam was associated with greater perceived benefits and fewer perceived barriers.

Causal beliefs. A number of studies confirmed the importance of causal beliefs in shaping help-seeking behavior (Begum et al., 2013; Blay et al., 2008; Feldman et al., 2015; Hamilton-West et al., 2010; Hurt et al., 2012; Morhardt et al., 2010). Attributing symptoms to psychosocial causes (versus biomedical) may have deterred formal help-seeking in some studies (Begum et al., 2013; Hurt et al., 2012; Morhardt et al., 2010). For example, Begum et al. (2013) found that patients who sought help were more likely to provide biomedical explanations for their SMCs, such as familial risk, while non-help seekers were more likely to cite psychosocial reasons, such as anxiety, stress, and poor sleep. Similarly, in another study, persons who sought help for SMCs were more likely to attribute problems to a lack of blood supply, whereas those who did not seek help for SMCs were more likely to attribute problems to loneliness, diet, and trauma (Hurt et al., 2012). Attributing symptoms to AD or dementia influenced intentions to seek help in several studies (Feldman et al., 2015; Hamilton-West et al., 2010; Werner, 2003a). One study showed that if the caregiver thought dementia was the cause of the person's symptoms, they were about six times more likely to seek formal help, whereas if they thought aging was the cause they were

significantly less likely to seek help (Feldman et al., 2015). Attributing symptoms to normal aging was mentioned by respondents in several studies and may result in a failure to seek medical help (Berwald et al., 2016; Jones et al., 2006; Leung et al., 2011; Levkoff et al., 1999; McCleary et al., 2013; Morhardt et al., 2010; N. Mukadam et al., 2011; N. Mukadam et al., 2015; Werner, 2004a). Affected individuals and caregivers may also attribute symptoms to health issues, such as pre-existing medical conditions, and medication side effects (Leung et al., 2011).

### 3. Psychosocial Factors

Social support, family structure and caregiving. Social support or informal help from family was identified in some studies as playing an important role in formal help-seeking (Devoy & Simpson, 2016; Hughes et al., 2009; Levkoff et al., 1999; Schrauf & Iris, 2012). Several studies noted that it was often the caregiver or a close family member who made the final decision to engage with the health care system (Chrisp et al., 2013; Garcia et al., 2014; Hinton et al., 2004; Koehn et al., 2012). In one study, the first choice of a source of help for participants responding to a vignette depicting a case of AD was a close family member (27% of 500 participants) (Blay et al., 2008).

Indeed, comments and recommendations from immediate and extended family members can play a fundamental role in recognizing the problem and deciding to seek help (McCleary et al., 2013; Streams et al., 2003). In a study of older adults with SMCs, people who sought formal help scored higher on social support seeking, while non-help seekers scored higher on distancing (Hurt et al., 2012). In another study of UK-based South Asian adults, anticipated social pressure from significant others was strongly associated with intention to seek help for memory problems (Hailstone et al., 2016). Family conflict may sometimes be involved in this decision making process if one party is in denial about the problem or reluctant to turn to outside sources of help

(Campbell et al., 2016; Chrisp et al., 2013; Garcia et al., 2014; Innes et al., 2014; Levkoff et al., 1999; N. Mukadam et al., 2011). Other family concerns, such as the health of another family member, financial hardship, lack of employment, and work-related stress, also may take precedence over getting help for a family member with memory problems (Morhardt et al., 2010).

Culturally shaped expectations about family responsibility may be a reason why some groups may be reluctant to seek outside help (Berwald et al., 2016; Braun et al., 1996; Casado et al., 2015). For instance, Vietnamese immigrants in one study expressed an agreement that older family members should be cared for at the home, and that only if symptoms were severe enough should a doctor be consulted (Braun et al., 1996).

Perceived threat or levels of concern or worry about symptoms. Perceived threat of disease is the combination of perceived susceptibility and perceived severity (Becker, 1974; Champion & Skinner, 2008), and may be an important predictor of intentions to seek help for SMCs. Several studies included in this review implicated level of concern or worry about symptoms as a factor influencing willingness to seek help and formal help-seeking behavior (Begum et al., 2013; Hodgson & Cutler, 2004; Williams et al., 2010). One study found that older adults who expressed higher levels of worry about their memory changes were more likely to have sought formal help (Hodgson & Cutler, 2004). A stronger sense of threat has also been shown to be directly and indirectly related to the decision to seek medical help through cognitive interpretation of identified symptoms (Qualls et al., 2015).

A lack of concern or worry about symptoms may lead some patients not to seek formal help (Begum et al., 2012; Begum et al., 2013). One study found that subjective memory impairment was not viewed by older adults in the study as a highly salient or concerning



symptom compared with other symptoms or disorders, like previous stroke or heart attack, headaches, arthritis, and bowel problems (Begum et al., 2012). Only 1 of 39 participants with significant subjective memory impairment had reported the symptom to a general practitioner (Begum et al., 2012).

Perceiving the symptoms of dementia to be severe and for the disease to have significant consequences and to be permanent has been shown to be associated with formal help-seeking intentions (Haralambous et al., 2014). Family caregivers in several studies reported that their fears and concerns about the physical safety of their elder led them to seek outside support and care (Levkoff et al., 1999; Morgan et al., 2014; N. Mukadam et al., 2011). In one study, caregivers reported experiencing extreme distress due to patient safety concerns in the time leading up to a clinic visit (Morgan et al., 2014).

Depression and anxiety. The impact of depression and anxiety on help-seeking is unclear. One study found that the presence of underlying depression or anxiety may contribute to a delay in formal help-seeking (Garcia et al., 2014). However, two studies found no significant differences between help-seekers for SMCs and non-help-seekers in levels of anxiety and depression (Hurt et al., 2012; Ramakers et al., 2009).

Stigma. Social stigma associated with dementia may play a role in help-seeking decisions. In four studies, stigma, shame and/or fear of labeling and discrimination emerged as barriers to help-seeking (Devoy & Simpson, 2016; Jones et al., 2006; N. Mukadam et al., 2015; Phillipson et al., 2015). Shame and stigma were cited as among the most difficult barriers to help-seeking for Asian-American families (Jones et al., 2006). In a study of UK-based South Asian adults, those who felt that seeking help for memory problems was embarrassing or stigmatizing were less likely to indicate that they would seek help from a doctor (Hailstone et al.,

2016). Similarly, Phillipson et al. (2015) found in their study of Australian adults that fear of labelling was associated with intentions to delay help-seeking for oneself and for a significant other, while fear of both labelling and discrimination were associated with intentions to seek help from no-one. Conversely, in another study, some community-dwelling elderly respondents considered a decrease in anxiety, embarrassment, and shame to be one of the benefits of obtaining a memory assessment (Werner, 2004a).

#### 4. Cognitive and Disease-Related Factors

Recognizing symptoms (self-assessment of memory). Awareness and recognition of memory problems or cognitive changes was reported in a number of studies as a factor influencing formal help-seeking (Campbell et al., 2016; Garcia et al., 2014; Leung et al., 2011; Peterson et al., 2016; Qualls et al., 2015; Streams et al., 2003; Werner & Heinik, 2004). In some studies, the caregiver was often the first to notice the symptoms of dementia, although affected individuals were also aware of their own symptoms (Feldman et al., 2015; Innes et al., 2014; McCleary et al., 2013). The majority of participants with dementia and their caregivers in one study pointed to their recognition of a gradual decline in memory and a sense of not being as “sharp” as before as the prompt for deciding whether or not to seek medical help (Leung et al., 2011). Participants in another study reported that the signs and symptoms of dementia were not always easy to identify, and an accumulation of subtle changes or more severe symptoms was the catalyst in motivating people to seek formal help (Garcia et al., 2014).

A study conducted in China showed that subtypes of dementia were associated with a delay in help-seeking (Zhao et al., 2015). Specifically, vascular dementia was recognized and brought to medical attention the earliest after the onset of symptoms, while the period between symptom recognition and help-seeking was the longest for frontotemporal dementia. This

suggests that the way in which symptoms manifest may influence help-seeking behavior.

Vascular dementia often involves a dramatic cognitive decline and may co-occur with the onset of cardiovascular events, while frontotemporal dementia symptoms tend to involve behavioral, language deterioration, and personality change with more preservation of memory.

Disease severity and functional impairment. Several studies found evidence that as the disease progresses, and cognitive and behavioral symptoms become increasingly severe and interfere with daily functioning, individuals were more likely to acknowledge the presence of a health condition and consult a family physician (Leung et al., 2011; McCleary et al., 2013; Morhardt et al., 2010; N. Mukadam et al., 2011; Peterson et al., 2016; Pires et al., 2012; Ramakers et al., 2009). For instance, the global severity and type of memory problems, such as forgetting names of family members, has been associated with formal help-seeking among the elderly (Pires et al., 2012). Caregivers in one study noted that issues with hygiene, finances, and safety triggered their concern and response (Garcia et al., 2014), suggesting that increasing disease severity and functional difficulties may prompt some individuals to seek help. A study of family caregivers conducted in five limited English proficiency communities found that for those who sought a formal diagnosis, they were most likely to do so when symptoms became so severe that they were no longer able to manage and cope on their own (Morhardt et al., 2010). Delaying seeking help until symptoms became unmanageable was also a major theme in a qualitative study of family caregivers (N. Mukadam et al., 2011) and in a qualitative study UK Black African and Caribbean communities (Berwald et al., 2016).

A large U.S. nationally representative study found an association between more severe dementia (as indicated by performance on the Dementia Severity Rating Scale, Clinical Dementia Rating, and Mini-Mental State Examination) and an increased likelihood of receiving

a cognitive assessment (Kotagal et al., 2015). Conversely, Frank et al. (1988) observed that the likelihood of having visited a health professional was significantly lower for cognitively impaired older adults in comparison to non-impaired older adults. Cognitive impairment or dementia itself may create barriers to utilizing health care services by making it difficult for people to understand or express their needs (Frank et al., 1988).

##### 5. Health care policies, access, and services

Perceptions of health systems, providers, services and treatments. A number of studies reported factors related to health systems, providers, services, and available treatments. Family physicians or general practitioners are often seen as a first point of formal contact when seeking help for memory problems (Leung et al., 2011; Low et al., 2011; McCleary et al., 2013; Ploeg et al., 2009; Samsi et al., 2014; Werner, 2003b). Begum et al. (2013) found that older adults who sought help for SMCs frequently expressed positive views about the health care system. Conversely, non-help seekers expressed concerns that they did not want to waste their physicians' time, that their physician might not take their complaints seriously, and commented that physicians should only be consulted for biological or physical symptoms. Reasons reported in other studies for a delay in seeking help were: not being sure what doctor to go to, difficulty in discussing memory problems with a physician, memory concerns not taken seriously, the doctor attributing concerns to normal aging, the doctor not mentioning problems, and the doctor's ambivalence toward getting a diagnosis (Boise et al., 1999; Connell et al., 2004; Koehn et al., 2012; Morgan et al., 2014; N. Mukadam et al., 2011).

Long waiting times, cost concerns (e.g., lack of Medicaid eligibility) and lack of access to dementia medications, lack of resources, and distance to services were sometimes mentioned as health care barriers (Casado et al., 2015; Innes et al., 2014; Juarez-Cedillo et al., 2014; Koehn et

al., 2012; Leung et al., 2011; Millard & Baune, 2009; Werner, 2004a). Health care access barriers may be created when services are not offered in the native language of the patient and caregiver, affecting formal help-seeking among some groups (Braun et al., 1996; Casado et al., 2015; Garcia et al., 2014). Negative experiences with health care providers were also raised, such as differing expectations about what could/should be done (Morhardt et al., 2010), or feeling that the physicians were uncaring or insensitive, lacked expertise, or did not provide information about the diagnosis, treatment and support options (Berwald et al., 2016; Dean et al., 2014; Hinton et al., 2006; Hinton et al., 2004; Hughes et al., 2009; Innes et al., 2014; Jones et al., 2006; Millard & Baune, 2009; N. Mukadam et al., 2011; Samsi et al., 2014). In a study of older adults with cognitive impairment and their family caregivers, many respondents mentioned the struggle they went through to make sense of the referral process (Samsi et al., 2014). Many respondents did not receive follow-up letters from their doctors, and the purpose and process of the referral had not been adequately explained to them. Some respondents also reported that the test results were communicated in a confusing way.

Perceptions of the usefulness of a cognitive examination were one of the primary predictors of help-seeking intentions in first degree relatives of persons with AD (Werner & Heinik, 2004). Higher levels of beliefs about the usefulness of treatments for AD has also been associated with greater intentions to seek help from professional sources (Werner, 2004b). One study in Brazil found that psychotherapy was considered the most useful intervention among participants responding to a vignette depicting a case of AD, followed by a variety of health behaviors like eating better and physical exercise (Blay et al., 2008). Psychotropic medications and other medical or psychiatric interventions were rarely considered useful and were often viewed as harmful.

Attitudes and beliefs of health care providers may also act as barriers and facilitators to formal help-seeking. Surveys of health care professionals found that some providers (15% of 109 GPs, nurses and other health care professionals) felt that an early dementia diagnosis is harmful to patients (Millard & Baune, 2009), and that many family physicians (70% of 197) believe that MCI, defined by the authors as “a condition characterized by newly acquired cognitive decline beyond what is expected for an individual’s age and education,” is caused by normal aging (Werner et al., 2013). Another survey found that family physicians are very knowledgeable about AD symptoms, and that greater knowledge about cognitive symptoms among family physicians was associated with recommendations that persons with AD seek help from specialists and primary care sources (Werner, 2007). Physicians are also more likely than the lay public to recommend professional sources of help-seeking (Werner, Heinik, et al., 2014).

Alternative care pathways. Opportunistic formal help-seeking, or seeking help during a check-up for another medical problem was mentioned in a few studies (Begum et al., 2013; Leung et al., 2011; McCleary et al., 2013). Two participants in one study described how their decisions to seek medical care were not planned, but instead the result of spontaneous decisions to disclose memory issues during regular visits to the doctor (Leung et al., 2011). In another study, two caregivers of persons with dementia sought formal help following a trauma (post-operative complications and a fall) that affected their care recipients’ functioning and safety, and resulted in a physician referral for cognitive testing (McCleary et al., 2013).

## **Discussion**

The aim of this study was to systematically review the empirical literature on formal help-seeking for SMCs or concerns about dementia among older adults, and to identify factors and theory-based hypotheses that influence the help-seeking process. There has been a notable

increase in research studies in this area, particularly in the last decade. We expect this trend to continue as dementia and Alzheimer's disease continue to gain attention due to a rapidly aging population, an already strained U.S. health care system, and the emergence of AD prevention trials that raise the possibility of future early stage disease-modifying interventions (Sperling, Mormino, & Johnson, 2014). While the existing literature has identified important factors that may influence the decision to seek formal help, there are still some key limitations and gaps for further research. Several conclusions can be drawn from the literature and will be described in the following paragraphs.

The 61 reviewed studies revealed a number of factors related to formal help-seeking variables and outcomes, including sociodemographic characteristics, knowledge, beliefs and personal experiences, psychosocial factors, cognitive and disease-related factors, and health care policies, access and services. This suggests that factors influencing formal help-seeking behavior for SMCs are multi-layered, with individual (e.g., knowledge and beliefs) interpersonal (e.g., social support), and structural or policy level factors (e.g., health care access) each playing a key role in the decision to seek help. Factors related to health systems, providers, and services emerged from many qualitative studies. Older adults may face a number of access barriers to health care services, such as socioeconomic or financial constraints, limited health care supply, and lack of quality health care and transportation, which can directly impede their use of health care services (Goins, Williams, Carter, Spencer, & Solovieva, 2005). Health care system constraints imposed on physicians, such as insufficient time, difficulty in accessing and communicating with specialists, low reimbursement, poor connections with community social service agencies, and a lack of interdisciplinary teams, may produce additional barriers for patients (Hinton et al., 2007). Given the significance of these issues to early diagnosis, future

research should investigate health care access and services as a predictor of help-seeking for SMCs and dementia concerns.

Several studies implicated perceived threat or concerns and worries about symptoms as a factor influencing help-seeking. Concerns have been raised that individuals with heightened perceived threat, or the “worried well,” may be at risk for misdiagnosis. Those who feel they are at a high risk for dementia, often due to a family history of the disease, may engage in symptom-seeking behavior in which they check for signs of AD or misinterpret a cognitive error as a symptom of the disease (Hodgson et al., 1999). Indeed, some studies have found that a significant proportion of individuals who seek help for memory complaints show no evidence of cognitive impairment after evaluation, or have low conversion rates to MCI and dementia (Alladi, Arnold, Mitchell, Nestor, & Hodges, 2006; Elfgren, Gustafson, Vestberg, & Passant, 2010). To date, few studies have examined potential factors associated with perceived threat of dementia that may impact help-seeking, and this remains an important area for further research.

One major limitation to this body of literature is a lack of standardization or consistency across studies. Most studies had varying definitions of concepts and constructs (including help-seeking), a lack of consistency in sampling criteria, and nearly all studies relied on investigator generated self-report questions on help-seeking behavior instead of validated measures. This makes any comparison of studies or synthesis of data across studies very challenging. In addition, most studies relied heavily on convenience sampling and obtained small study samples with limited racial and ethnic representation. Racial and ethnic disparities in dementia diagnoses are a major public health concern in the U.S., and we found that several sampled studies reported racial/ethnic differences in factors related to help-seeking, including perceived benefits and barriers to obtaining a diagnosis (Connell et al., 2009), symptom attribution or appraisal (Levkoff



et al., 1999), and language barriers in health care settings (Braun et al., 1996; Casado et al., 2015). Thus, population-based or nationally representative studies on formal help-seeking behavior with more racially and ethnically diverse samples that can offer cross-group comparisons are needed.

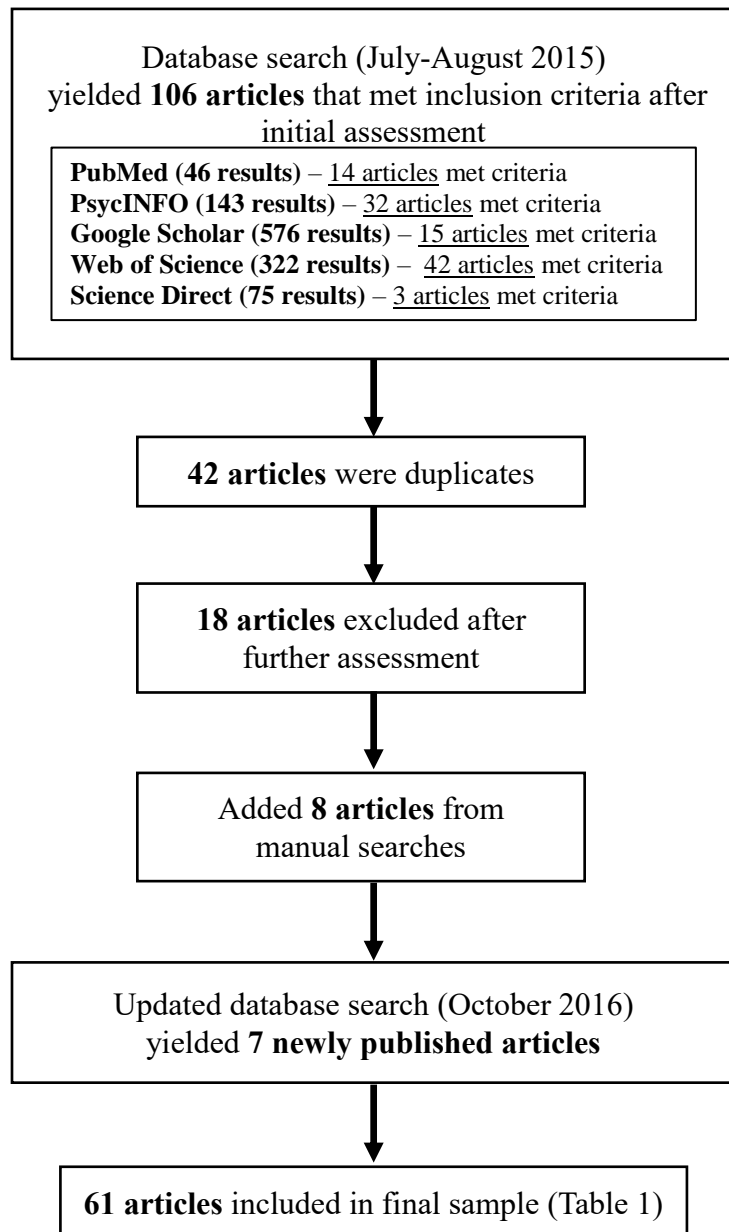
Another major limitation to the sampled literature is that most studies were not guided by theoretical frameworks. Only 17 studies used a theoretical model or framework, 6 of which relied on the Health Belief Model. The Health Belief Model is a widely used framework that has been largely successful in predicting preventive and screening behaviors (Becker, 1974; Champion & Skinner, 2008; Janz & Becker, 1984), and has been used to examine health-related decision making and help-seeking behavior in a variety of areas. Yet the model is limiting in its narrow focus on individual level factors, such as personal perceptions and beliefs, and may not give appropriate consideration to broader societal or contextual influences on behavior. Future research might benefit from employing a socio-ecological framework or approach that incorporates structural, social policy or community level influences on help-seeking behavior for SMCs or dementia concerns (McLeroy et al., 1988).

There are some limitations to this systematic review. First, the review focused specifically on empirical studies of factors influencing formal help seeking for SMCs or concerns about developing dementia. While the use of the term “help seeking” served to narrow the search to relevant articles, it is possible that some studies may have used different terminology or may have been missed in our initial database search. We worked to prevent this by doing a secondary search of reference lists and journal databases. Nonetheless, it is possible we may have missed some relevant articles in our search, a limitation of any systematic review. Second, the studies varied greatly methodologically, with different samples, study designs, and

conceptual frameworks. For instance, some studies focused exclusively on older adults with SMCs, cognitive impairment, or dementia, while others interviewed caregivers, physicians, or the general public. Sample sizes and composition varied, and both qualitative and quantitative studies were equally present in the literature. The great variation between studies made it challenging to synthesize or compare findings. As such, a meta-analysis or statistical comparison of help-seeking findings across studies was not possible.

In sum, this review sought to systematically and critically examine the literature on formal help-seeking behavior for SMCs and dementia concerns. While this area of research has emerged relatively recently, there is already a rapidly growing literature. Nonetheless, many studies to date were conducted with convenience-based samples of limited size and racial/ethnic representation, and few used theoretical frameworks and validated measures. Our findings suggest a need for larger population-based studies, as well as theoretically-driven studies that take into account not only factors at the individual level but also macro level influences on help-seeking, such as health care access and provision of services. The identification of specific factors involved in formal help-seeking for SMCs or dementia concerns may help to increase early detection and diagnosis of dementia and benefit the work of health care professionals when evaluating patients' memory complaints.

**Figure 2-1:** Flow Diagram



**Table 2-1:** Summary of Studies Identified in Systematic Review of Help-seeking Behavior for SMCs (N = 61)

References	Study Aims / Theory	Sample Characteristics	Study Design	Main findings
*Begum et al., 2012  Country: UK	To investigate factors associated with subjective memory impairment (SMI), salience of SMI in comparison with other symptoms, and help-seeking for SMI	126 older adults (mean age = 74.6, SD = 6.9); SMI reported in 66.7% (n=84) of the sample, and 31% reported SMI to a significant degree	Convenience sampling; sample drawn from a list of registered patients aged 65 and older at two Primary Care services  Quantitative (face-to-face structured interview)	Only one participant with significant subjective memory impairment (SMI) had reported this to their general practitioner. Despite the prevalence and salience of SMI, it was the symptom least likely to be reported.
Begum et al., 2013  Country: UK	To compare the experiences of older adults who sought formal help for SMCs and those who did not	9 older adults with SMCs who sought formal help (median age = 78 years); 9 older adults with SMCs who did not seek formal help (median age = 74 years).	Participants recruited from a local specialist memory assessment service (formal help-seekers), and selected from a community survey (non-formal help-seekers)  Qualitative (household face-to-face interviews; thematic framework analysis)	Three themes emerged as facilitators and barriers to formal health service use: concern (e.g., feeling worried or concerned about memory problems), causation (causal beliefs ranged from biomedical to psychosocial), and perceptions of general practitioner (e.g., barriers to talking with a GP). Informal help-seeking (i.e., talking to family and friends and adopting self-help strategies) and alternative pathways to care (i.e., being visible to health services and opportunistic help-seeking) also emerged as playing a role in help-seeking.

<p>Berwald et al., 2016</p> <p>Country: UK</p>	<p>To identify and explore barriers to help-seeking for memory problems within UK Black African and Caribbean communities</p>	<p>50 people (age range = 18-85 years old); 28 Black African, 14 Black Caribbean, 7 Black British, and 1 Indo-Caribbean</p>	<p>Participants purposively recruited from community groups and snowball sampling</p> <p>Qualitative (semi-structured interviews with a vignette portraying a person with symptoms of dementia; thematic analysis)</p>	<p>Five themes emerged, identifying obstacles to seeking health service help for dementia: 1) Is forgetfulness indicative of dementia, 2) Is dementia an illness of BME communities, 3) should people seek health service help for memory problems, 4) fear of lifestyle changes and confidentiality, and 5) privacy and family duty within individual's culture. Participants felt seeking professional help for forgetfulness would be dependent upon persistence, severity, and impact upon everyday life. They believed that help-seeking should be delayed until a "crisis point" or until forgetfulness was a serious enough problem to warrant help-seeking.</p>
--	---	---	--	---

<p>*Blay et al., 2008</p> <p>Country: Brazil</p>	<p>To investigate the lay public's attitudes toward help-seeking and preferences for AD treatment</p> <p>Leventhal Model of Stress and Coping (Common-Sense Model of Illness Representations)</p>	<p>500 household residents over 18 years old (18-29 years: 31.6%; 30-49 years: 41.6%; 50-65 years: 26.8%)</p>	<p>Cross-sectional, population-based study; Participants selected using random sampling with multiple stages and a substitution strategy</p> <p>Quantitative (Household face-to-face structured interviews with vignette depicting a case of AD)</p>	<p>The majority of respondents reported that their first choice source of help would be from close family (27%), followed by a psychologist (15%), neurologist (13%), self-help group (12%), and a general practitioner (12%). Seeking medical help was associated with recognizing that the vignette depicted someone with a 'psychiatric condition.' Seeking religious help was associated with recognition of the psychiatric condition and being Catholic. Psychological and self-help were associated with lower education and being Catholic.</p>
<p>Boise et al., 1999</p> <p>Country: USA</p>	<p>To explore the experiences of family caregivers in seeking a diagnostic assessment for persons with symptoms of dementia</p>	<p>38 families and 53 total individuals attended the focus groups (mean age of caregivers: 54 years; mean age of patients: 80 years); 191 family caregivers completed and provided useable data on the mailed questionnaire (72% response rate).</p>	<p>Family caregivers of persons with AD were identified through an Alzheimer's Disease Assessment Clinic, and through enrollment in a federally-funded demonstration project</p> <p>Qualitative and quantitative (focus group sessions and a mailed structured questionnaire)</p>	<p>Four factors were identified in delaying diagnosis: caregivers' lack of knowledge or reluctance to seek help, and patient, family, and physician-related factors. Of respondents who reported a delay of 12 months or more between symptom recognition and diagnosis, 68% reported factors related to their interactions with physicians.</p>

<p>*Braun et al., 1996</p> <p>Country: USA</p>	<p>To explore the perceptions of Vietnamese refugees with respect to caregiving, dementia, and help-seeking</p>	<p>39 family caregivers participated in focus groups (age range: 19-77)</p>	<p>Four focus groups were conducted with family caregivers, and eight key informants were interviewed</p> <p>Qualitative (focus groups and key informant interviews)</p>	<p>Most family caregivers in the focus groups agreed that older family members should be cared for at home by the family, and that only if dementia symptoms are bad would they consider seeking help from a physician. Younger participants were more receptive to the idea of taking their family member to a specialist.</p>
<p>Campbell et al., 2016</p> <p>Country: UK</p>	<p>To investigate the subjective experience of those living with undiagnosed and then, over time, diagnosed dementia, and to elicit the meanings that such transitions hold for those concerned</p>	<p>7 older adults with undiagnosed/diagnosed dementia (age range = 68-77), and 5 co-residents /carers</p>	<p>Purposive sampling</p> <p>Qualitative (face-to-face semi-structured interviews in participant's homes; participants interviewed alone or in diads; grounded theory)</p>	<p>Results showed a four-phase sequential model of diagnostic transition: 1) becoming self-aware -&gt; seeking outside help; 2) being referred -&gt; receiving a clinic appointment; 3) undergoing tests -&gt; being told what's wrong; 4) adjusting to the diagnosis -&gt; negotiating everyday expectations.</p>

<p>Casado et al., 2015</p> <p>Country: USA</p>	<p>To examine the experience of dementia caregiving among family caregivers of older Korean Americans with dementia symptoms</p>	<p>23 family caregivers (mean age = 67.3; SD = 8.7; range = 43-76)</p>	<p>Purposive sampling; Participants recruited with the assistance of Korean American community organizations and a county office on aging</p> <p>Qualitative (focus group interviews; thematic analysis)</p>	<p>Despite the fact that all caregivers had taken their family member with dementia symptoms to Korean American physicians, only 7 caregivers reported that their care recipient had undergone a memory test and none of the caregivers reported that a full clinical assessment for dementia had been conducted. Caregivers were reluctant to have their family members tested due to the fear of receiving a formal diagnosis. Reported barriers to receiving care related to language and lack of access to formal care services.</p>
<p>Chrisp et al., 2012</p> <p>Country: UK</p>	<p>To describe the decision-making process by which individuals other than the person with dementia symptoms make the decision to first engage with health care professionals (HCPs)</p> <p>Parson's Model of the Sick Role</p>	<p>20 family caregivers</p>	<p>Participants were invited to a memory clinic</p> <p>Qualitative (document analysis of pre-existing case study materials developed in 2009 as part of a service evaluation; open-ended questioning; thematic analysis)</p>	<p>Four subthemes emerged within the overarching theme of bounded autonomy in decision-making. Decisions to engage with the health care system are socially contested and negotiated. Very often it is the family member or carer who takes the first step to engage with HCPs.</p>



<p>Connell et al., 2004</p> <p>Country: USA</p>	<p>To examine attitudes of caregivers and physicians toward assessing and diagnosing dementia, with an emphasis on how a diagnosis is disclosed</p>	<p>52 caregivers (mean age = 63, age range = 40-85) participated in nine focus group interviews, and 39 physicians participated in eight interviews</p>	<p>Participants were recruited from three Alzheimer's Disease Centers at the University of Michigan, Case Western Reserve University, and the Oregon Health &amp; Sciences University</p> <p>Qualitative (semi-structured interviews; focus groups)</p>	<p>Caregivers reported resistance from physicians when they tried to obtain a dementia diagnosis. They were told sometimes that their family members' symptoms were due to aging. Caregivers described a number of advantages to obtaining a diagnosis. With a diagnosis, they felt they would have been more patient, understanding, and less apt to blame their family member for his or her actions. Physicians reported feeling frustrated by the limited amount of time they have to spend with people with dementia. They also reported that the primary advantages of receiving a diagnosis are that family members could find out what is wrong, begin planning for the future, and be referred to services.</p>
---	---	---	---	--

<p>Connell et al., 2009</p> <p>Country: USA</p>	<p>To investigate the benefits of and barriers to obtaining a dementia diagnosis for black and white adults affected by AD</p>	<p>178 family members of individuals with AD (median age = 57; range = 27-81); Black (n=75) and White (n = 103)</p>	<p>Convenience sampling; Participants recruited from two U.S. metropolitan areas (Boston and Atlanta) using multiple strategies and sources</p> <p>Quantitative (structured survey); respondents rated the importance of 8 benefits of and 16 barriers to obtaining a dementia diagnosis</p>	<p>Around three-quarters of participants rated three of eight potential benefits to obtaining a diagnosis as extremely high: finding out what was wrong with their family member, making future plans, and obtaining disease information. Over 60% responded that receiving a diagnosis might qualify their family member for drug treatment. Over one-quarter of the sample endorsed three treatment-related barriers: the perceptions that very little can be done, the lack of a cure for AD, and the belief that no effective AD treatments exist. Black participants endorsed access-related barriers more frequently than whites.</p>
<p>Dean et al., 2014</p> <p>Country: UK</p>	<p>To explore the experiences of people with mild cognitive impairment (MCI) and their advocates with respect to their contact with healthcare services</p>	<p>23 people with MCI (mean age = 77.8; range 63-86) and 20 advocates (mean age = 69; range 42-84)</p>	<p>People with MCI were recruited from research databases and memory clinics affiliated with six mental health trusts in the south of England; Relatives or friends of the participants with MCI were recruited via those people</p> <p>Qualitative (semi-structured interviews conducted at</p>	<p>Most patients reported positive or neutral experiences contacting their general practitioner. Those who reported negative experiences felt that their problem had not been addressed, that they weren't kept informed, or that the general practitioner was dismissive of their memory concern. Many found the process too lengthy or difficult, or irrelevant to their symptoms. Among advocates, a majority reported that there were some negative experiences - a common</p>

			participants' homes or local hospital departments; grounded theory)	one being that the general practitioner did not pay sufficient attention to the problem. Common complaints were perceived lack of information about the diagnosis and treatment or support options.
Devoy and Simpson, 2016  Country: UK	To identify factors that may increase intentions to seek help for an early dementia diagnosis  Theory of Planned Behavior (TPB)	22 community-dwelling older adults (age range = 50-69 years) participated in focus groups; 95 community-dwelling older adults (age range = 50-69) from Dublin and Kildare were administered a questionnaire	Opportunistic sampling of community dwelling older adults living in Kildare and Dublin  Qualitative (three focus groups, structured interviews, inductive content analysis) and Quantitative (questionnaire)	Facilitators of help-seeking were family, friends, and peers alongside well informed health professionals; Barriers were a lack of knowledge, fear, loss, stigma, and inaccessible services. The main predictors of help-seeking in the regression analysis were knowledge of dementia and subjective norms.
Feldman et al., 2015  Country: UK	To investigate family carers' accounts of first onset and symptoms attribution and explore the effects of carer attributions on help-seeking	84 carers of people with dementia (mean age = 66; SD = 12.6; range = 36-88)	Carers were recruited through their general practitioner  Quantitative and Qualitative (semi-structured interviews)	Memory loss was often reported as the first symptom at onset. 39% of the sample delayed help-seeking. If the carer attributed the person's symptoms to dementia or unknown causes, they were more likely to seek help immediately. If the carer attributed the symptoms to aging, personality, life events or other illnesses, they were less likely to seek help.

Frank et al., 1988  Country: USA	To examine the relationships between cognitive impairment and utilization of services by elderly persons residing in the community	207 elderly persons, which were divided into two groups: cognitively impaired (mean age = 78) and nonimpaired (mean age = 73)	A subgroup of participants were sampled from the East Baltimore Health Survey  Quantitative (administered a questionnaire to each elderly individual or a proxy)	Persons with cognitive impairment were significantly less likely to visit a health care professional than those in the nonimpaired group.
Galvin et al., 2008  Country: USA	To examine the psychosocial factors explaining older adults' intention to undergo screening for AD  Health Belief Model Theory of Reasoned Action Self-Efficacy Social Support Behavioral Model of Health Services Use	1,039 community-dwelling older adults (mean age: 62.7; range: 50-97 years)	Population-based study; random digit dialing used to recruit participants in urban, suburban and rural settings in Missouri  Quantitative (structured interviews completed over the telephone; 82% response rate; 72% completer rate)	Older adults who were more likely to exhibit intention to screen for AD had higher perceived benefits from diagnosis, greater knowledge about dementia and its consequences, greater self-efficacy to perform the behavior, positive preventive health behaviors (e.g., cancer screening and dental examinations), and greater perceived susceptibility/threat of dementia.

<p>Garcia et al., 2014</p> <p>Country: Canada</p>	<p>To describe the experiences of francophone Canadians with dementia and their caregivers on the pathway to dementia diagnosis</p>	<p>7 diads, which included 7 persons with dementia (age range: 64-84), and 7 caregivers (age range: mid-40s to late 80s)</p>	<p>Convenience sampling; recruited recently diagnosed French-speaking patients in a Memory Disorder Clinic.</p> <p>Qualitative (face-to-face semi-structured interviews)</p>	<p>Delays in diagnosis had several different causes: a desire to seek medical help from a French-speaking specialist, complications related to hospitalizations, families not agreeing on cause of symptoms, and the presence of underlying depression. In all cases, the caregiver noticed signs that something wasn't right which prompted them to contact the family physician. Signs and symptoms of dementia were not easy for respondents to identify. Respondents talked about the importance of having a long-standing relationship with a health care provider, who would be able to identify and evaluate the symptoms.</p>
<p>Hailstone et al., 2016</p> <p>Country: UK</p>	<p>To use the theory of planned behavior to develop and validate a questionnaire by assessing whether attitudes of UK-based people from South Asian backgrounds are associated with willingness to seek help from a GP for memory problems; and to investigate the</p>	<p>58 people (mean age = 60 years; range = 18-83) took part in qualitative interviews; 51 people completed the online questionnaire (mean age = 50.6 years; range = 18-85)</p>	<p>Purposively sampled community organizations and then snowballing to reach participants outside these organizations.</p> <p>Qualitative (focus group interviews; vignette methodology; thematic analysis) and quantitative (structured questionnaire)</p>	<p>Perceived social pressure from significant others was the strongest predictor of willingness to seek help. Willingness to seek help was strongly associated with attitudes about the benefits of seeing a doctor for memory problems, attitudes that were related to specific beliefs about what doctors can do to help. Attitudes predicted 77% of the variance in willingness to seek help, but no relationship</p>

	<p>relationship between knowledge about dementia and willingness to seek help in this population</p> <p>Theory of Planned Behavior</p>			<p>was found with dementia knowledge.</p>
<p>*Hamilton-West et al., 2010</p> <p>Country: UK</p>	<p>To examine the utility of the common-sense model of illness representation for understanding lay perceptions of dementia and predicting intention to seek help for a relative with mild or moderate symptoms of dementia</p> <p>Common-Sense Model of Illness Representations</p>	<p>118 undergraduate psychology students (mean age: 20; range: 18-45 years) from a University in England</p>	<p>Participants randomly assigned to one of two conditions: mild or moderate</p> <p>Quantitative (use of vignettes indicative of mild or moderate dementia, followed by a structured and open-ended questionnaire)</p>	<p>Participants were more likely to indicate an intention to seek professional help if they identified the problem as dementia, perceived the symptoms to be severe, and perceived the consequences to be severe. They were less likely to indicate an intention to seek professional help if they identified the problem as stress or due to psychological causes.</p>

<p>Haralambous et al., 2014</p> <p>Country: Australia</p>	<p>To determine the barriers and enablers to accessing Cognitive Dementia and Memory Services for people with dementia and their families from Chinese and Vietnamese backgrounds</p> <p>The Cultural Exchange Model</p>	<p>7 carers of Vietnamese people (mean age = 62; SD = 11.10); 6 carers of Chinese people (mean age = 54; SD = 14.35); 8 Vietnamese and 4 Chinese community workers; 8 health professionals who worked with Vietnamese community and 31 who worked with Chinese community</p>	<p>Carers were recruited through current service providers, community workers, and advisory board members</p> <p>Qualitative (face-to-face interviews and focus groups; thematic analysis)</p>	<p>There were five main categories for carers' experiences of barriers and enablers to help-seeking: 1) carer distress, 2) misunderstanding of dementia, 3) seeking a diagnosis following an event or crisis, 4) carers needing more knowledge about dementia, and 5) both negative and positive experiences of the service system. Community workers identified key barriers as level of community knowledge and perceptions of dementia, and delayed diagnosis. Health professionals identified: late diagnosis, issues within the communities, and families, as barriers to help-seeking.</p>
<p>*Hinton et al., 2006</p> <p>Country: USA</p>	<p>To investigate dementia neuropsychiatric symptom severity, help-seeking patterns, and family unmet needs for professional help</p>	<p>38 elderly with dementia (mean age = 74.9; SD = 7.7), and their caregivers (mean age = 59.7; SD = 17.4)</p>	<p>Participants were from the Sacramento Area Latino Study on Aging</p> <p>Quantitative and Qualitative (face-to-face semi-structured interviews in caregivers' homes)</p>	<p>80% of Latino families (n=30) caring for the elderly with one or more dementia neuropsychiatric symptoms reported that they mentioned one or more symptoms to their primary care physicians. Frequently reported unmet need for professional help were for counseling and information, in-home help, and improved access to health care. 57.9% indicated that they needed more professional help.</p>

<p>*Hinton et al., 2004</p> <p>Country: USA</p>	<p>To describe pathways to dementia diagnosis from the perspectives of family caregivers and to compare help-seeking patterns across three ethnic groups</p>	<p>39 family caregivers (10 blacks, 14 Chinese, 15 Anglo European-Americans)</p>	<p>Convenience sampling; participants were from a larger study of stress, coping, and service utilization, recruited from a variety of sources (Alzheimer's Association, physician referrals, etc.)</p> <p>Qualitative (semi-structured interviews)</p>	<p>Narratives of help-seeking could be broken down into two events: an initial phase in which the first symptoms are brought to the attention of a physician, and a later phase in which care is sought from additional helpers within the health care system, culminating in a final diagnosis. In 74% of cases, a family member initiated help-seeking (usually wives or daughters), and in 21% of interviews health care providers first recognized symptoms. Secondary formal helpers often became involved through self-referral by families. Four general types of pathways to diagnosis were found: smooth pathways, crisis events pathways, fragmented pathways, and dead-end pathways. These pathways varied significantly across the three ethnic groups.</p>
---	--	--	---	---



<p>Hodgson et al., 1999</p> <p>Country: USA</p>	<p>To describe symptom-seeking behavior and explore the degree to which symptom-seeking takes place in a sample of middle aged children of parents with AD, and in those with no family history of AD</p>	<p>25 children of a parent with AD (mean age = 46; SD = 4), and 25 comparison group individuals with no family history of AD (mean age = 45; SD = 3)</p>	<p>Children of a parent with AD were recruited through two community organizations serving families of persons with AD, and a nursing home facility; the comparison group was recruited through friendship networks of the original sample and were matched on characteristics</p> <p>Quantitative and Qualitative (face-to-face structured interviews)</p>	<p>Symptom-seeking was categorized into three behaviors: repeatedly checking oneself for signs of AD, Interpreting cognitive changes as symptoms of the disease, and asking for external validation of concerns. Memory change was the most commonly mentioned concern, and respondents often made the connection between their parents' disease and their own memory loss. External validation was sought from family, friends, and professionals. Children of a parent with AD and women engaged in more symptom-seeking than the comparison group.</p>
<p>*Hodgson &amp; Cutler, 2004</p> <p>Country: USA</p>	<p>To examine the predictors of help-seeking behavior for personal concerns about developing AD among middle-aged persons</p> <p>Health Belief Model</p>	<p>99 adult children (mean age = 49.9; SD = 5.4) with a living parent with a diagnosis of probable AD, and 70 adults (mean age = 49.4; SD = 5.5) with no parental history of AD</p>	<p>Matched comparison-group study; Several organizations (e.g., Alzheimer's association chapter and hospital-based clinics) assisted in recruitment</p> <p>Quantitative (telephone interviews conducted with elements of both a structured and open-ended questionnaire)</p>	<p>Respondents who are concerned about developing AD are more likely to seek help from informal rather than formal sources. Significant correlates of help-seeking emerged within three clusters: memory assessment, AD experience, and socio-demographics. The most salient predictor of help-seeking behavior was AD experience (whether respondent was the child of a parent with AD).</p>

<p>*Hughes et al., 2009</p> <p>Country: USA</p>	<p>To examine the experiences of African American caregivers who were given a diagnosis of AD for a family member</p> <p>Health Belief Model</p>	<p>17 African American caregivers (mean age = 59.8 years; range = 42-80) with a family member that was given a diagnosis of Alzheimer's disease</p>	<p>Participants were recruited from the African American Dementia Outreach Partnership (AADOP)</p> <p>Qualitative (semi-structured face-to-face interviews; grounded theory)</p>	<p>Study findings revealed a lack of knowledge about AD and a general belief that memory loss and functional decline was a normal part of aging. The formal health care system was identified as a barrier to early diagnosis for the majority of caregivers.</p>
<p>*Hurt et al., 2012</p> <p>Country: UK</p>	<p>To investigate the factors underlying the decision to seek help in people with SMCs using the Common-Sense Model of Illness Perception as a framework</p> <p>Common-Sense Model of Illness Perception</p>	<p>98 older adults with SMCs aged 50 years or older, including 60 who attended a memory clinic (mean age = 71.6 years; SD = 8.3; range = 24-91) and 38 non-help seekers (mean age = 76.1 years; SD = 9.0; range = 55-91)</p>	<p>Older adults with SMCs attending the Manchester Memory Clinic were invited to take part in the study, while additional participants with SMCs were recruited from community groups and sheltered housing projects</p> <p>Quantitative (household face-to-face structured questionnaire)</p>	<p>Illness perceptions predicted help-seeking behavior, including social comparison and causal attributions. Attributions of memory problems to loneliness was predictive of not seeking help, whereas attributions of memory problems to lack of blood supply to the brain and perceiving that memory was worse than others was predictive of seeking help. Those who sought help were more likely to have relatives with dementia.</p>

<p>Innes et al., 2014</p> <p>Country: UK</p>	<p>To explore the difficulties and satisfactions with the diagnostic processes and post-diagnostic support provided to individuals with dementia and their families in a rural region in Scotland</p>	<p>6 people with dementia (age range: 58-82), and 12 family members (age range: 45-80)</p>	<p>Participants recruited through their local memory service with the support of Community Mental Health Teams' staff</p> <p>Qualitative (face-to-face semi-structured interviews)</p>	<p>Carers reported that recognizing memory problems led them to eventually seek help, however, many admitted to denying the problems or seeing them as a part of aging. Participants reported varying lengths of the diagnostic process, some reporting long wait times and others receiving a quick diagnosis. Three issues emerged as part of the disclosure process: being fully informed about the diagnosis, the way the information was communicated, and the impact delivery of the diagnosis on care and support received.</p>
<p>*Jones et al., 2006</p> <p>Country: USA</p>	<p>To examine factors influencing attitudes toward AD and treatment-seeking that may create barriers to timely diagnosis and treatment of AD among Asian Americans of different national origins (Chinese, Japanese, and Korean)</p>	<p>23 Japanese Americans, 13 Korean Americans, and 26 Chinese Americans residing in California. Participants had a range of ages from 23 through 83</p>	<p>Participants were recruited from among the friends and families of the group leaders or from the clientele of community organizations</p> <p>Qualitative (focus groups; content analysis)</p>	<p>Symptoms of memory loss were familiar to most participants as a sign of AD. The perceived conflict between Asian and Western medicines and methods emerged as an issue among focus group participants, and information related to how a diagnosis of AD is obtained was a bit sketchy. Cultural beliefs exerted an influence on how participants regarded AD. Shame and stigma were found to be among the most difficult barriers to care for many Asian families, while other barriers included normalization and denial.</p>

<p>Juarez-Cedillo et al., 2014</p> <p>Country: Mexico</p>	<p>To identify caregivers' social representations of dementia in a family member and examine how awareness of social representations influences seeking treatment during the first stages of dementia</p> <p>Social representations framework</p>	<p>Primary caregivers (mean age = 55) of 8 adults aged 60 or older with a diagnosis of dementia</p>	<p>The data come from a cross-sectional study called the "Study on Aging and Dementia in Mexico" (SADEM); the study sample was randomly selected from all adults with a diagnosis of dementia in the larger study</p> <p>Qualitative (face-to-face semi-structured interviews conducted in caregivers' homes)</p>	<p>The dimensions that emerged from the data were: knowledge of the disease, feelings toward dementia, and difficulties for diagnosis. Difficulties for diagnosis was formed by 7 subthemes: meanings attributed to dementia, causes and motivations in seeking treatment, explanations for treatment, strategies for coping with the illness, resources for treatment, support structures and family bonds.</p>
<p>*Koehn et al., 2012</p> <p>Country: Canada</p>	<p>To understand how Chinese-Canadian persons with dementia and their families experience pathways to a diagnosis of dementia</p> <p>Critical constructionist and intersectional framework, and Levkoff et al.'s help-seeking model</p>	<p>10 diads: 10 Chinese-Canadian persons diagnosed with probable dementia aged 72-86, and their family caregivers</p>	<p>Participants were recruited by the coordinator of the Chinese Resource Center of the Alzheimer's Society of British Columbia</p> <p>Qualitative (semi-structured interviews)</p>	<p>The role of family caregivers in carer-seeking was more influenced by structural factors than traditional Chinese cultural norms. When caregivers recognized the symptoms as problematic, they sought out more information, often from a family physician who was the first point of contact for 70% of diads. Gender-based power imbalance between female caregivers and male physicians may have contributed to delays in diagnosis.</p>

<p>Kotagal et al., 2015</p> <p>Country: USA</p>	<p>To explore factors associated with clinical evaluations for cognitive impairment among older adults in the U.S.</p>	<p>297 older adults with dementia (mean age = 84.3; range = 70-110)</p>	<p>Nationally representative community-based cohort study; participants were from the Aging, Demographics, and Memory Study, a subsample of the Health and Retirement Study</p> <p>Quantitative (structured interviews)</p>	<p>55.2% of participants reported no history of clinical cognitive evaluation by a physician. Marital status was a significant predictor of receiving a clinical cognitive evaluation.</p>
<p>*Leung et al., 2011</p> <p>Country: Canada</p>	<p>To understand the experiences of Anglo-Canadians with dementia and their carers regarding the sequence of symptoms and events that preceded the diagnosis, their beliefs about cognitive changes, and the types of help sought during personally significant moments of transition.</p>	<p>6 persons with dementia (age range: 50s-70s), and 7 family carers</p>	<p>Participants were recruited from a hospital-affiliated geriatrics clinic and the Alzheimer's Society of Calgary.</p> <p>Qualitative (semi-structured interviews; thematic analysis)</p>	<p>Five themes emerged: becoming aware of memory problems, attributing meanings to symptoms, initiating help-seeking, acknowledging the severity of cognitive changes, and obtaining a definitive diagnosis. Persons with dementia noticed their symptoms before their carers, however, these symptoms were perceived as ambiguous, and were normalized and attributed to health problems. A diagnosis was obtained when more severe cognitive problems emerged. Carers were actively involved in the help-seeking process.</p>

<p>*Levkoff et al., 1999</p> <p>Country: USA</p>	<p>To understand the help-seeking experiences of minority family caregivers of elderly affected by dementia, including the role of religious/ethnic factors</p> <p>Levkoff et al.'s help-seeking model</p>	<p>40 caregivers (mean age = 50) from African American (n=10), Chinese American (n=10), Puerto Rican (n=10), and Irish-American (n=10) groups</p>	<p>Families were recruited through presentations at local nursing homes, caregiver support groups, adult day health centers, and home health care agencies, as well as referrals from physicians.</p> <p>Qualitative (semi-structured interviews; thematic analysis)</p>	<p>Between group differences were found in themes of most stages of the help-seeking process. The findings suggest that religious/ethnic factors may play a role in both aiding and impeding help-seeking among caregivers. For instance, themes of turning to ethnic or religious service organizations were present in the narratives from each group. Narratives contained themes of difficulty accessing care from mainstream organizations due to language barriers and lack of awareness on the part of administrators about cultural preferences.</p>
<p>*Low et al., 2011</p> <p>Country: Australia</p>	<p>To explore help-seeking strategies and acceptance of services among a national sample of Italian, Greek and Chinese compared to third generation Australians</p>	<p>350 Italian (mean age = 58.4; range = 18-89), 414 Greek (mean age = 61.4; range = 18-94), 437 Chinese (mean age = 46.6; range = 18-89), and 500 third generation Australians (mean age = 55.8; range = 18-94)</p>	<p>Cross-sectional telephone survey; households were randomly selected from the Australian national telephone directory</p> <p>Quantitative (vignettes describing character with mild or moderate symptoms and behaviors of dementia)</p>	<p>General practitioners (55%) were most frequently suggested as a source of help for the character in the vignette, followed by community organizations (27%), family (26%), and a specialist (14%). As compared with third generation Australians, significantly more racial minority participants indicated that they would seek help from their families.</p>

<p>McCleary et al., 2013</p> <p>Country: Canada</p>	<p>To explore the experiences of South Asian Canadian persons with dementia and their family carers prior to dementia diagnosis</p>	<p>6 persons with dementia (mean age = 80; range = 74-84) and 8 of their family carers</p>	<p>Participants recruited from an agency that provides an Adult Day Program for South Asians, and from flyers distributed to community health and social services agencies.</p> <p>Qualitative (face-to-face semi-structured interviews)</p>	<p>Early signs were attributed to aging or personality, and family carers modified physical or social environments because of these symptoms prior to seeking medical attention. Help-seeking was delayed up to 4 years even when significant symptoms were present. Recognition of the problem was influenced by safety concerns, emergency of new symptoms following trauma, and treatment for other health problems.</p>
<p>Millard and Baune, 2009</p> <p>Country: Australia</p>	<p>To compare patient experiences in dealing with dementia with the perceived role of health care providers in providing dementia care</p>	<p>20 patients with a diagnosis of dementia (range = 70-99), and informants, and 114 health professionals (53% general practitioners and 33% nurses, with the remainder other health professionals)</p>	<p>Patients/family members were referred by their general practitioner</p> <p>Quantitative (survey distributed at dementia forums and by mail to general practitioners) and Qualitative (face-to-face interviews with patients and families; grounded theory)</p>	<p>Patients often noticed their symptoms before their general practitioner and seek help and support. Patients and carers expressed distress caused by their doctor's failure to initiate timely assessments or to offer advice or support. Some general practitioners did not wish to provide dementia services and many were unaware of the benefits of early diagnosis. Older patients tend to consult with older general practitioners but older general practitioners are less likely to be aware of dementia diagnosis and management guidelines.</p>

<p>Morgan et al., 2014</p> <p>Country: Canada</p>	<p>To explore the experiences of rural family caregivers in the period leading up to a diagnostic assessment, and their experiences in the six months following diagnosis</p>	<p>46 caregivers who were caring for 30 patients at baseline, and 33 of those 46 caregivers at six months</p>	<p>Convenience sampling from the Rural and Remote Memory Clinic; Longitudinal study design</p> <p>Qualitative (semi-structured interviews conducted at baseline and six months later)</p>	<p>Most caregivers reported first noticing symptoms two years prior to diagnosis. There was a prevalent "need to know" among caregivers that drove the help-seeking process. Caregivers believed that the diagnosis would have the benefits of 'naming it,' 'accessing treatment,' 'knowing what to expect,' and 'receiving guidance.'</p>
<p>Morhardt et al., 2010</p> <p>Country: USA</p>	<p>To understand how 5 limited English proficiency community groups conceptualize dementia, and the reasons why persons in these communities seek or do not seek an evaluation for cognitive impairment</p>	<p>48 family caregivers of elderly with cognitive impairment in five limited English proficiency communities (Arab, Assyrian, Bosnian, Hindi, and Urdu) in the Chicago metropolitan area</p>	<p>Sample consisted of family caregivers of elderly identified as having cognitive impairment who were enrolled in the Alzheimer's Disease Demonstration Grants to States (ADDGS) project</p> <p>Qualitative (grounded theory methodology with combination of observation and face-to-face interviews)</p>	<p>Those who did not seek an evaluation tended to believe memory loss was a normal part of aging and that family and social problems were more of a concern. They also often had a negative past history with doctors. If they believed stress caused the memory problem, they were less likely to undergo an evaluation. Those who sought an evaluation wanted treatment to slow the progression of the disease, wanted to get help for symptoms, and were pursuing a cure.</p>



<p>*Mukadam et al., 2011</p> <p>Country: UK</p>	<p>To explore the link between attitudes toward help-seeking for dementia and help-seeking pathways in the minority ethnic and indigenous population</p>	<p>18 family carers (mean age = 57; range: 27-85) of people with dementia from the major UK ethnic groups (4 White UK, 5 South Asian, 5 Black, 1 White Irish, 1 White other, 1 Asian other, and 1 Chinese)</p>	<p>Purposive sampling; carers were referred by clinicians they knew, or recruited from an ethnically diverse London inner city mental health trust.</p> <p>Qualitative (semi-structured interviews)</p>	<p>In comparison to the indigenous population, minority ethnic caregivers tended to delay help-seeking until they could no longer cope or until others commented on the problems. They often believed a diagnosis alone was purposeless and that it is the family's responsibility to look after their own elders. Cognitive impairment was the most common reason for seeking help, and the most common pathway to diagnosis was via the general practitioner.</p>
<p>Mukadam et al., 2015</p> <p>Country: UK</p>	<p>To explore South Asian peoples' interpretation of cognitive symptoms and reluctance behind seeking medical help for those symptoms; and to explore what might encourage earlier help-seeking in order to devise an intervention to encourage timely diagnosis</p>	<p>53 English or Bengali speaking South Asian adults (mean age = 57, range = 18-83) without a known diagnosis of dementia</p>	<p>Purposively sampled participants from South Asian community centers and then through snowballing from those contacts and researchers' personal or professional contacts</p> <p>Qualitative (focus groups and individual interviews; vignette methodology; interpretative phenomenological analysis)</p>	<p>Participants identified four main barriers to timely diagnosis: 1) barriers to help-seeking for memory problems, 2) the threshold for seeking help for memory problems, 3) ways to overcome barriers to help-seeking, and 4) what features an educational resource should have. Specific barriers were grouped into individual, societal/community, and health care system levels. Individual-level barriers included memory problems are an inevitable and normal part of aging, memory problems are not an illness, and individuals or families can make memory problems better. Societal level</p>

				barriers included stigma of diagnosis and good families look after people with dementia themselves. Health care system barriers included lack of knowledge of help available.
Peterson et al., 2016  Country: USA	To assess caregivers' sources of information, barriers to seeking and receiving information, and preferences for information sources	27 caregivers (mean age = 58.5 years, range = 34-86 years) of persons with dementia	Caregivers were identified through a prospective sequential search of their specialty memory/dementia clinic schedule for upcoming initial/new patient evaluations, and were reached via telephone  Qualitative (semi-structured interviews; content analysis)	Emerging themes were: 1) Barriers to seeking information often result from knowledge gaps, rather than reluctance to assume the caregiver role, 2) Most caregivers currently receive insufficient information. Most caregivers could not identify the trigger that led them to seek a medical evaluation and caregiver information, but some were vaguely aware that "something wasn't right" for a period of time. The gradual accumulation of symptoms prompted them to seek a medical evaluation/information. Triggers also included an abrupt memory or cognitive decline, problematic behavioral symptoms, declining functional capabilities, or increased caregiver frustration.
Phillipson et al., 2015  Country: Australia	To investigate associations between dementia-attitudes and help-seeking intentions of Australian adults in response to two	611 adults (mean age = 54.4, age range = 45-60 years) without a diagnosis of dementia	Participants were recruited via targeted advertisements placed on the Facebook pages of users aged 40-65; links to online survey were also distributed	82.2% of participants indicated they would seek help from a general practitioner for themselves, and 78.7% for a proxy in response to scenarios. Personal avoidance and fear of labelling were associated with intentions to

	scenarios: that they themselves had the early signs of dementia (Scenario 1) or that a significant other was experiencing the early signs (Scenario 2)		nationally via the 'National Seniors' newsletters, and through Alzheimer's Australia national database of email and via their national newsletters  Quantitative (online survey questionnaire)	delay help-seeking. Fear of both Labelling and Discrimination were associated with intentions to seek help from no-one. Personal avoidance was associated with intentions to delay proxy help-seeking and a reduced likelihood of seeking help by phone and, with fear of discrimination, via a GP. Fear of Labelling was also associated with an intention to delay proxy help-seeking.
Pires et al., 2012  Country: Portugal	To determine the severity and type of memory difficulties presented by elderly patients who seek for clinical help, as compared to the memory difficulties reported by subjects in the community	871 non-demented subjects older than 50 years, of which 581 were recruited in the community (mean age = 67.4) and 290 with SMCs in a clinical setting (mean age = 67.6)	Participants were either recruited in the community or in a clinical setting  Quantitative (semi-structured interview)	Forgetting names of family members or friends' contributed more to the variance of the total SMC score in the clinical sample (18%) as compared to the community sample. Forgetting names may play a key role in SMCs in a clinical setting and may likely drive people to seek clinical help.
*Ploeg et al., 2009  Country: Canada	To examine where older adults seek help in caring for a parent with dementia and the factors associated with their identification of community health and support services as sources of assistance	1,152 adults aged 50 and over	Cross-sectional descriptive survey; Random digit dialing from a list of all residents of Hamilton  Quantitative (telephone interviews; vignettes raised issues related to parental dementia)	When faced with parental dementia, the highest percentage of participants identified a physician and the physician's office staff as sources of support. This source was named by 25 percent of respondents as their first choice, and overall by 37 percent of respondents. The odds of identifying physicians as a source of support increased by 40% if

				caregivers were female, and by 250% for participants with higher levels of education. Knowing where to find information about community support services was associated with an increased likelihood of mentioning physicians and home health services as sources of assistance.
Qualls et al., 2015  Country: USA	To test relationships among cognitive and motivational factors in predicting medical help-seeking intentions for AD symptoms  The Cognitive Impairment Response Model	280 community residents awaiting jury service (mean age = 40.74; SD = 13.22; range = 18-74)	Participants were recruited through a jury pool in a midsized western city  Quantitative (questionnaire packet; vignette depicting prototypical early symptoms of AD in a hypothetical mother)	The impact and identification of AD symptoms, appraisals of risk, and attribution of the scenario to AD were modest, yet all of these factors made contributions to the prediction of medical help-seeking intentions. Motivational factors had particularly influential direct and indirect effects on help-seeking intentions.
*Ramakers et al., 2009  Country: The Netherlands	To investigate which factors determine why people with SMCs seek medical attention	33 cases with SMCs who sought help aged 50 years or older (mean age = 62; SD = 8.6), and 83 controls with SMCs who did not seek help aged 50 years or older (mean age = 65.1; SD = 10.3)	Case-control study design with cases selected from Maastricht Memory Clinic and controls from the Maastricht Aging Study  Quantitative (mailed questionnaire; 63% response rate for cases)	Cases who sought help for SMCs scored lower on memory self-efficacy and quality of life, and were more worried due to a family history of dementia, as compared to controls who did not seek help. Relatives of cases also reported more deterioration in daily functioning as compared to relatives of controls.

<p>Samsi et al., 2014</p> <p>Country: UK</p>	<p>To obtain an insider perspective on the lived experience of the assessment journey for people with cognitive impairment and their carers</p>	<p>20 diads: 27 persons with cognitive impairment (ages 65-80+), and 26 carers (ages 65-80+)</p>	<p>Purposeful sampling; Participants were identified at weekly memory services' multidisciplinary team meetings</p> <p>Qualitative (semi-structured interviews; thematic analysis)</p>	<p>Feelings of confusion, uncertainty and anxiety over waiting times was a dominate sub-theme on the assessment journey. Participants often felt without support to manage their uncertainties, emotions and did not know where to turn for support. Some were very critical about the systemic process of assessment and diagnosis disclosure. For most participants, consultations with a general practitioner were the first time they had discussed memory problems beyond the family.</p>
<p>*Schrauf &amp; Iris, 2011</p> <p>Country: USA</p>	<p>To examine the duration and direction of pathways-to-diagnosis of dementia among African Americans and Hispanics, with a particular concentration on those with very long pathways</p>	<p>41 family caregivers (mean age = 57.4; SD = 12.2) of 42 older adult patients (26 African American, 16 Hispanic; mean age = 79.2; SD = 9.3)</p>	<p>Participants were recruited through senior centers, caregiver support groups, adult day care centers, caregiver information days, newspaper advertisements, and radio announcements.</p> <p>Quantitative (structured retrospective recall interviews with timeline card sort)</p>	<p>Short pathways to diagnosis were dominated by stepwise movement toward diagnosis and some ambivalence around symptom recognition. Long pathways were marked by a shift away from movement toward diagnosis but toward family taking over key tasks.</p>

<p>*Streams et al., 2003</p> <p>Country: USA</p>	<p>To examine the population seeking care at two memory clinics and the triggers causing caregivers to seek diagnostic assessment for a family member</p>	<p>416 caregivers (mean age = 61.5; SD = 12.5) of patients (mean age = 76.4; SD = 9.2) seeking a memory assessment</p>	<p>Recruited family members involved in the decision to seek a memory assessment for a family member at two memory disorders clinics</p> <p>Quantitative (structured survey with two open-ended questions)</p>	<p>Changes in the patient (cognitive, personality/behavioral, physical, or unspecified) accounted for 81% of 903 trigger events reported. Memory loss was the most frequent trigger reported, followed by disorientation and recommendations (lay or professional).</p>
<p>Wackerbarth &amp; Johnson, 2002</p> <p>Country: USA</p>	<p>To identify the benefits and barriers perceived by family caregivers of persons who have been through a diagnostic assessment for dementia</p> <p>Health Belief Model</p>	<p>528 family caregivers of persons who had been through a diagnostic assessment in last 4 years  Caregiver mean age: 61.3 years (range: 28-88)  Care receiver mean age: 76.2 (range: 44-95)</p>	<p>Sample drawn from two memory disorder clinics affiliated with University of Kentucky's Alzheimer's Disease Research Center</p> <p>Quantitative (mailed survey packet; 71.7% response rate)</p>	<p>Perceived benefits included confirming a medical condition, access to treatment, and help preparing for the caregiver role, while barriers were related to worries about the impact of the diagnosis, the belief that memory loss was a normal part of aging, and financial concerns. A greater number of barriers was associated with longer delays in seeking an assessment.</p>
<p>*Watari &amp; Gatz, 2004</p> <p>Country: USA</p>	<p>To examine help-seeking behaviors for dementia and Alzheimer's disease among older Korean Americans</p>	<p>Study 1: 60 Korean American and 212 non-Korean American Alzheimer's disease patients (44 African American, 79 Latino, 89 European American)</p> <p>Study 2: 109 Korean</p>	<p>Study 1 used the database from the University of Southern California/St. Barnabas Alzheimer's Disease Diagnostic and Treatment Center</p> <p>Study 2 recruited a</p>	<p>Findings from study 1 showed that both Korean American and non-Korean American groups waited 3-4 years before seeking help and sought help when memory decline was accompanied by other problems. Among Korean Americans, those living with family were more impaired than</p>

		Americans (age range 18-73)	convenience sample of Korean American adults from two Los Angeles Christian Korean churches  Quantitative (structured interview questionnaires, vignette)	those living alone, suggesting a longer delay in seeking help. Findings from study 2 showed that those who were more familiar with dementia symptoms indicated they would seek help.
*Werner, 2003a  Country: Israel	To examine factors influencing intention to seek a cognitive status evaluation in the presence of memory problems  Health Belief Model	186 community dwelling elderly persons aged 53 to 90 (mean age = 64.1; SD = 7.7)	Convenience sampling  Quantitative (face-to-face structured interviews)	Intention to seek a cognitive status assessment was associated with stronger social influence (cues to action), greater perceived benefits, and fewer perceived barriers. Participants' intentions were higher when scenarios described a family history of Alzheimer's disease.
*Werner, 2003b  Country: Israel	To assess relationships between knowledge about symptoms of AD and help-seeking intention among the lay public  Health Belief Model	150 community dwelling elderly persons aged over 45 (mean age = 59.9; SD = 11.9) who did not have a close relative with AD	Convenience sampling  Quantitative (face-to-face structured interviews)	Participants consistently reported intention to seek more help from professional than non-professional sources. Higher levels of knowledge about symptoms of AD was associated with greater intentions to seek help.
*Werner, 2004a  Country: Israel	To examine lay persons' beliefs about the helpfulness of interventions for AD and its correlates, and to assess the relationship between	206 Jewish Israeli adults (mean age = 59.7, SD = 8.1)	Convenience sampling  Quantitative (face-to-face structured interviews; vignette varying the severity of AD)	The lay public endorsed the use of nonpharmacological treatments more than pharmacological ones. Engagement in social activities and participation in a support group were the treatment approaches most recommended,

	these recommendations and help-seeking behaviors			while the use of physical restraints and isolation were the least recommended. Findings showed that participants would seek more help from professional than non-professional sources. Beliefs about the usefulness of treatments were related to intentions to seek help from professionals.
Werner, 2004b Country: Israel	To assess the lay public's recommendations about treatments for AD and its correlates, and the relationship between these recommendations and help-seeking behaviors  Health Belief Model	79 community dwelling elderly persons aged over 55 (mean age = 67.6; SD = 9.9)	Convenience sampling  Qualitative (semi-structured interviewing)	Respondents reported structural (e.g., access to health services) and psychosocial barriers (e.g., stigma) to undergoing a memory assessment. Most indicated they would only seek help if memory problems became serious enough to affect daily functioning.
*Werner, 2007 Country: Israel	To assess family physicians' recommendations for help-seeking for a person with AD, and their relation to knowledge about symptoms of the disease	395 Israeli family physicians (mean age = 48.6; SD = 10.6)	Nationally representative sample of family physicians  Quantitative (computer assisted telephone interview; structured interview, vignettes describing 71-year old man with AD varying by disease stage)	With the exception of the spouse and children, family physicians were more likely to recommend seeking help from professional than non-professional sources, with the main professional source being primary care. More knowledge about cognitive symptoms was associated with recommendations to seek help from specialists and primary care sources.



<p>*Werner &amp; Heinik, 2004</p> <p>Country: Israel</p>	<p>To examine the factors influencing intentions to seek a cognitive status evaluation among first-degree relatives of persons with AD</p>	<p>93 first-degree relatives of persons with AD (mean age = 50.7; SD = 8.1)</p>	<p>Participants were recruited from a large memory clinic</p> <p>Quantitative (telephone interviews)</p>	<p>First degree relatives reported moderate intentions to seek a cognitive status examination. Their willingness to seek an examination was related to the characteristics of the first degree relatives (income and subjective memory), the characteristics of the patients (behavioral problems), the caregiving characteristics (primary caregiver), and to the perceptions of barriers associated with the examination.</p>
<p>*Werner et al., 2013</p> <p>Country: Israel</p>	<p>To explore family physicians' familiarity, knowledge, help-seeking, and treatment preferences regarding MCI</p>	<p>197 family physicians (mean age = 50.1; SD = 9.2); range: 28-69)</p>	<p>Convenience sample of family physicians from one of the largest health maintenance organizations in Israel</p> <p>Quantitative (structured questionnaire)</p>	<p>The majority of participants had heard about MCI but a third of those familiar with the term reported knowing almost nothing about it. Participants' objective knowledge was good regarding several causes of MCI, but 70% reported it to be caused by normal aging. Help-seeking and treatment preferences corresponded with the literature on MCI. The first source of help recommended was the family physician, followed by the spouse and children of the person with MCI.</p>

<p>Werner et al., 2014</p> <p>Country: Israel</p>	<p>To compare help-seeking preferences of family physicians and the lay public in the area of MCI</p>	<p>197 family physicians (mean age = 50.12; SD = 9.20) and 517 persons aged 45 and over from the lay public (mean age = 59.98; SD = 9.79)</p>	<p>Convenience sample of family physicians from one of the largest health maintenance organizations in Israel; convenience sample of community-dwelling older adults</p> <p>Quantitative (structured questionnaire)</p>	<p>The majority of both samples reported that family physician, spouse, and children are the most highly recommended sources of help-seeking. Regarding professional sources of help-seeking, a higher percentage of the physicians than the lay public sample consistently recommended seeking help from nurses, social workers and psychiatrists, but a higher percentage of the lay public recommended turning to a neurologist for help.</p>
<p>*Williams et al., 2010</p> <p>Country: USA</p>	<p>To describe individuals' reasons for participating in cognitive screening and reasons to pursue testing after screening across 4 ethnic groups (African Americans, Afro-Caribbean, European American, and Hispanic American)</p>	<p>119 adults from four ethnic groups: African American (mean age = 66; SD = 13.78), Afro-Caribbean (mean age = 66.74; SD = 9.89), European American (mean age = 73.36; SD = 11.77), and Hispanic American (mean age = 69.09; SD = 11.16)</p>	<p>Screening sites were churches, senior centers, and health fairs in south Florida, which served primarily minority older adults</p> <p>Quantitative and Qualitative (structured interviews)</p>	<p>More African Americans and European Americans were concerned about their memory. More Hispanic Americans planned to seek professional help if needed. Hispanic Americans were most optimistic about treatment.</p>

<p>Zhao et al., 2015</p> <p>Country: China</p>	<p>To examine the duration between estimated symptom onset and initial help in a multisite naturalistic study of clinical practice, and to explore the potential factors associated with the increased delay from onset to help seeking.</p>	<p>576 persons with dementia (mean age = 73.07; SD = 9.49) and their informants</p>	<p>Participants with suspected cognitive impairment were recruited from 28 participating memory clinics at tertiary (level 3) hospitals across broad geographic regions in China</p> <p>Quantitative (Clinical Report Form)</p>	<p>Individuals with a positive family history of dementia had a longer duration between the first noticeable symptom to the first visit seeking diagnosis or treatment. Compared with other types of dementia, people with vascular dementia were referred for diagnosis earliest, followed by Alzheimer's disease and frontotemporal dementia. Subtypes of dementia, family history and education level were associated with an increased delay in help seeking.</p>
<p>* Article was also included in Werner, P., Goldstein, D., Karpas, D. S., Chan, L., &amp; Lai, C. (2014). Help-seeking for dementia: a systematic review of the literature. <i>Alzheimer Dis Assoc Disord</i>, 28(4), 299-310.</p> <p>Note: Table uses terminology from each individual study</p>				

**Table 2-2: Background of Studies (N=61)**

	<b>n (%)</b>
<i>Publication Time Period</i>	
<1999	5 (8.2)
2000-2009	21 (34.4)
2010-2016	35 (57.4)
<i>Country</i>	
Australia	4 (6.6)
Brazil	1 (1.6)
Canada	6 (9.8)
China	1 (1.6)
Israel	8 (13.1)
Mexico	1 (1.6)
Portugal	1 (1.6)
The Netherlands	1 (1.6)
UK	15 (24.6)
USA	23 (37.7)
<i>Methodology</i>	
Quantitative	27 (44.3)
Qualitative	26 (42.6)
Mixed Methods	8 (13.1)
<i>Sample Size</i>	
<100	33 (54.1)
100-1,000	25 (41.0)
>1,000	3 (4.9)
<i>Theoretical Approach</i>	
Yes	17 (27.9)
No	44 (72.1)

**Table 2-3: Summary of Domains and Factors Related to Formal Help-Seeking**

List of Factors by Domain and Category	Summary/Examples of Key Study Findings
<b>1. Sociodemographic characteristics</b>	
<b>Age</b>	Younger age is associated with greater perceived benefits of seeking help (Werner, 2003a) and intent to seek a medical evaluation for symptoms of AD (Qualls et al., 2015)
<b>Gender</b>	Female gender is associated with increased AD knowledge (Hodgson & Cutler, 2004), and women are more likely to engage in symptom-seeking and formal help-seeking behavior than men (Hodgson et al., 1999)
<b>Race/ethnicity</b>	Racial/ethnic differences are found in perceived benefits and barriers to obtaining a diagnosis, symptoms attribution or appraisal, and general patterns of formal help-seeking behavior. For instance, African American adults endorsed access-related barriers more frequently than Whites (Connell et al., 2009). Some racial/ethnic minority groups may also encounter language barriers in health care settings that could deter help-seeking (Braun et al., 1996; Casado et al., 2015)
<b>Marital status</b>	Being married is associated with receiving a clinical evaluation for cognitive impairment (Kotagal et al., 2015)
<b>Income</b>	Higher income is associated with lower intentions to seek a cognitive status examination (Werner and Heinik, 2004)
<b>Education</b>	Older adults with higher levels of education are more likely to seek out information sources about AD (Hodgson & Cutler, 2004)
<b>2. Knowledge, beliefs, and personal experiences</b>	
<b>Knowledge about symptoms of dementia</b>	Older adults with more AD knowledge report more help-seeking from formal networks (Hodgson & Cutler, 2004), more willingness to be tested for cognitive problems (Galvin et al., 2008), and more intention to seek help from professional sources (Werner, 2003b)
<b>Personal experience with dementia</b>	Older adults who have a parent with AD are more likely to seek out informal and formal sources of help (Hodgson & Cutler, 2004), and older adults with SMCs who sought help at a memory clinic were more likely to be worried about a family history of dementia compared to those who had not sought help (Ramakers et al., 2009)
<b>Perceived benefits and barriers to obtaining a diagnosis</b>	Intention to seek a cognitive status exam is associated with greater perceived benefits and fewer perceived barriers (Werner 2003a). Family caregivers who sought a formal evaluation for memory problems did so because they wanted treatment to slow the disease progression, they wanted to get help for bothersome symptoms, and/or they were hoping to find a cure (Morhardt et al., 2010)
<b>Causal beliefs</b>	Attributing dementia symptoms to psychosocial causes rather than biomedical (Begum et al., 2013; Hurt et al., 2012; Morhardt et al., 2010), or attributing symptoms to normal aging (Berwald et al., 2016; Jones et al., 2006; Leung et al., 2011; Levkoff et al., 1999) may deter formal help-seeking. For instance, patients who sought help are more likely to provide biomedical explanations for their SMCs, such as familial risk, while non-help-seekers are more likely to cite psychosocial reasons, such as anxiety, stress, and poor sleep (Begum et al., 2013)

### 3. Psychosocial factors

<b>Social support, family structure, and caregiving</b>	Anticipated social pressure from significant others is strongly associated with intention to seek help (Hailstone et al., 2016). Older adults with SMCs who sought formal help scored higher on social support seeking, while non-help seekers scored higher on distancing (Hurt et al., 2012)
<b>Perceived threat</b>	Older adults with higher levels of worry and concern about memory changes are more likely to seek help (Hodgson & Cutler, 2004). A stronger sense of threat is directly and indirectly related to the decision to seek medical help through cognitive interpretation of identified symptoms (Qualls et al., 2015)
<b>Depression &amp; anxiety</b>	The presence of underlying depression or anxiety may contribute to a delay in formal help-seeking (Garcia et al., 2014)
<b>Stigma</b>	Stigma, shame and/or fear of labeling and discrimination emerged as barriers to help-seeking (Devoy & Simpson, 2016; Jones et al., 2006; N. Mukadam et al., 2015; Phillipson et al., 2015)

### 4. Cognitive & disease-related factors

<b>Recognizing symptoms</b>	Awareness and recognition of memory problems/cognitive changes is implicated in formal help-seeking (Campbell et al., 2016; Garcia et al., 2014; Leung et al., 2011). Gradual decline in memory and a sense of not being as "sharp" as before are prompts for deciding whether to seek help (Leung et al., 2011)
<b>Disease severity &amp; functional impairment</b>	As the disease progresses and cognitive and behavioral symptoms become more severe, individuals are likely to consult a health care provider (Leung et al., McCleary et al., 2013; Morhardt et al., 2010; Pires et al., 2012). Caregivers noted that issues with hygiene, finances, and safety triggered their concern and response (Garcia et al., 2014)

### 5. Health care policies, access, & services

<b>Perceptions of health systems, providers, services, and treatments</b>	Long waiting times, cost concerns, lack of access to medications, lack of resources, and distance to services were mentioned as help-seeking barriers (Casado et al., 2015; Innes et al., 2014; Juarez-Cedillo et al., 2014; Koehn et al., 2012). Older adults who sought help for SMCs frequently expressed positive views about the health care system, while non-help seekers expressed concerns that they did not want to waste their physicians' time, that their physician might not take their complaints seriously, and commented that physicians should only be consulted for biological or physical symptoms (Begum et al., 2013). Perceived usefulness of cognitive examinations and treatments for AD are associated with help-seeking intentions (Werner & Heinik, 2004; Werner 2004b)
<b>Alternative care pathways</b>	Decisions to seek help are not always planned, but instead result from spontaneous decisions to disclose memory issues during regular doctor visits or following a major medical trauma (Leung et al., 2011; McCleary et al., 2013)

SMCs: Subjective memory complaints

## References

- Alladi, S., Arnold, R., Mitchell, J., Nestor, P. J., & Hodges, J. R. (2006). Mild cognitive impairment: applicability of research criteria in a memory clinic and characterization of cognitive profile. *Psychol Med*, *36*(4), 507-515.
- Alzheimer's Association. (2014). 2014 Alzheimer's Disease Facts and Figures. Retrieved from [http://www.alz.org/downloads/Facts\\_Figures\\_2014.pdf](http://www.alz.org/downloads/Facts_Figures_2014.pdf)
- Alzheimer's Association. (2016). 2016 Alzheimer's Disease Facts and Figures. Retrieved from [http://www.alz.org/documents\\_custom/2016-facts-and-figures.pdf](http://www.alz.org/documents_custom/2016-facts-and-figures.pdf)
- Alzheimer's Association, & Centers for Disease Control and Prevention. (2013). *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*. Retrieved from <http://www.alz.org/publichealth/downloads/2013-RoadMap.pdf>
- Andersen, R., & Newman, J. F. (1973). Societal and individual determinants of medical care utilization in the United States. *Milbank Mem Fund Q Health Soc*, *51*(1), 95-124.
- Becker, M. H. (1974). The Health Belief Model and Personal Health Behavior. *Health Education Monographs*, *2*, 324-473.
- Begum, A., Morgan, C., Chiu, C.-C., Tylee, A., & Stewart, R. (2012). Subjective memory impairment in older adults: aetiology, salience and help seeking. *Int J Geriatr Psychiatry*, *27*(6), 612-620.
- Begum, A., Whitley, R., Banerjee, S., Matthews, D., Stewart, R., & Morgan, C. (2013). Help-seeking response to subjective memory complaints in older adults: toward a conceptual model. *Gerontologist*, *53*(3), 462-473.
- Berwald, S., Roche, M., Adelman, S., Mukadam, N., & Livingston, G. (2016). Black African and Caribbean British Communities' Perceptions of Memory Problems: "We Don't Do Dementia." *PLoS One*, *11*(4), e0151878.
- Blay, S. L., Furtado, A., & Peluso, E. T. (2008). Knowledge and beliefs about help-seeking behavior and helpfulness of interventions for Alzheimer's disease. *Aging Ment Health*, *12*(5), 577-586.
- Boise, L., Morgan, D. L., Kaye, J., & Camicioli, R. (1999). Delays in the diagnosis of dementia: Perspectives of family caregivers. *Am J Alzheimers Dis Other Demen*, *14*(20), 20-26.
- Braun, K. L., Takamura, J. C., & Mougeot, T. (1996). Perceptions of dementia, caregiving, and help-seeking among recent Vietnamese immigrants. *J Cross Cult Gerontol*, *11*(3), 213-228.
- Campbell, S., Manthorpe, J., Samsi, K., Abley, C., Robinson, L., Watts, S., . . . Keady, J. (2016). Living with uncertainty: Mapping the transition from pre-diagnosis to a diagnosis of dementia. *J Aging Stud*, *37*, 40-47.
- Casado, B. L., Lee, S. E., Hong, M., & Hong, S. (2015). The Experience of Family Caregivers of Older Korean Americans With Dementia Symptoms. *Clinical Gerontologist*, *38*(1), 32-48.
- Champion, V. L., & Skinner, C. S. (2008). The Health Belief Model. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health Behavior and Health Education* (pp. 45-62). San Francisco, CA.
- Chrisp, T. A. C., Tabberer, S., & Thomas, B. D. (2013). Bounded autonomy in deciding to seek medical help: Carer role, the sick role and the case of dementia. *J Health Psychol*, *18*(2), 272-281.

- Clark, P. C., Kutner, N. G., Goldstein, F. C., Peterson-Hazen, S., Garner, V., Zhang, R., & Bowles, T. (2005). Impediments to timely diagnosis of Alzheimer's disease in African Americans. *J Am Geriatr Soc*, 53(11), 2012-2017.
- Clement, S., Schauman, O., Graham, T., Maggioni, F., Evans-Lacko, S., Bezborodovs, N., . . . Thornicroft, G. (2015). What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. *Psychol Med*, 45(1), 11-27.
- Connell, C. M., Boise, L., Stuckey, J. C., Holmes, S. B., & Hudson, M. L. (2004). Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians. *Gerontologist*, 44(4), 500-507.
- Connell, C. M., Roberts, J. S., McLaughlin, S. J., & Carpenter, B. D. (2009). Black and White Adult Family Members' Attitudes Toward a Dementia Diagnosis. *J Am Geriatr Soc*, 57(9), 1562-1568.
- Daker-White, G., Beattie, A. M., Gilliard, J., & Means, R. (2002). Minority ethnic groups in dementia care: A review of service needs, service provision and models of good practice. *Aging Ment Health*, 6(2), 101-108.
- de Vugt, M. E., & Verhey, F. R. J. (2013). The impact of early dementia diagnosis and intervention on informal caregivers. *Progress in Neurobiology*, 110, 54-62.
- Dean, K., Jenkinson, C., Wilcock, G., & Walker, Z. (2014). Exploring the experiences of people with mild cognitive impairment and their caregivers with particular reference to healthcare - a qualitative study. *Int Psychogeriatr*, 26(3), 475-485.
- Dennis, C. L., & Chung-Lee, L. (2006). Postpartum depression help-seeking barriers and maternal treatment preferences: a qualitative systematic review. *Birth*, 33(4), 323-331.
- Devoy, S., & Simpson, E. E. (2016). Help-seeking intentions for early dementia diagnosis in a sample of Irish adults. *Aging Ment Health*, 1-9.
- Eisenberg, D., Hunt, J., & Speer, N. (2012). Help seeking for mental health on college campuses: review of evidence and next steps for research and practice. *Harv Rev Psychiatry*, 20(4), 222-232.
- Elfgrén, C., Gustafson, L., Vestberg, S., & Passant, U. (2010). Subjective memory complaints, neuropsychological performance and psychiatric variables in memory clinic attendees: a 3-year follow-up study. *Arch Gerontol Geriatr*, 51(3), e110-114.
- Facione, N. C. (1993). Delay versus help seeking for breast cancer symptoms: a critical review of the literature on patient and provider delay. *Soc Sci Med*, 36(12), 1521-1534.
- Feldman, L., Wilcock, J., Thuné-Boyle, I., & Iliffe, S. (2015). Explaining the effects of symptom attribution by carers on help-seeking for individuals living with dementia. *Dementia*, 1471301215593185.
- Fitten, L. J., Ortiz, F., & Ponton, M. (2001). Frequency of Alzheimer's disease and other dementias in a community outreach sample of Hispanics. *J Am Geriatr Soc*, 49(10), 1301-1308.
- Frank, R. G., German, P. S., Burns, B. J., & Johnson, W. (1988). Use of services by cognitively impaired elderly persons residing in the community. *Hospital & Community Psychiatry*, 39(5), 555-557.
- Galvin, J. E., Fu, Q., Nguyen, J. T., Glasheen, C., & Scharff, D. P. (2008). Psychosocial determinants of intention to screen for Alzheimer's disease. *Alzheimers Dement*, 4(5), 353-360.



- Garcia, L. J., McCleary, L., Emerson, V., Léopoldoff, H., Dalziel, W., Drummond, N., . . . Silvius, J. (2014). The Pathway to Diagnosis of Dementia for Francophones Living in a Minority Situation. *The Gerontologist*, *54*(6), 964-975.
- Goins, R. T., Williams, K. A., Carter, M. W., Spencer, M., & Solovieva, T. (2005). Perceived barriers to health care access among rural older adults: a qualitative study. *J Rural Health*, *21*(3), 206-213.
- Gulliver, A., Griffiths, K. M., & Christensen, H. (2012). Barriers and facilitators to mental health help-seeking for young elite athletes: a qualitative study. *BMC Psychiatry*, *12*, 157.
- Hailstone, J., Mukadam, N., Owen, T., Cooper, C., & Livingston, G. (2016). The development of Attitudes of People from Ethnic Minorities to Help-Seeking for Dementia (APEND): a questionnaire to measure attitudes to help-seeking for dementia in people from South Asian backgrounds in the UK. *Int J Geriatr Psychiatry*.
- Hamilton-West, K. E., Milne, A. J., Chenery, A., & Tilbrook, C. (2010). Help-seeking in relation to signs of dementia: a pilot study to evaluate the utility of the common-sense model of illness representations. *Psychol Health Med*, *15*(5), 540-549.
- Haralambous, B., Dow, B., Tinney, J., Lin, X., Blackberry, I., Rayner, V., . . . LoGiudice, D. (2014). Help seeking in older Asian people with dementia in Melbourne: Using the cultural exchange model to explore barriers and enablers. *J Cross Cult Gerontol*, *29*(1), 69-86.
- Hebert, L. E., Weuve, J., Scherr, P. A., & Evans, D. A. (2013). Alzheimer disease in the United States (2010-2050) estimated using the 2010 census. *Neurology*, *80*(19), 1778-1783.
- Hinton, L., Chambers, D., Velásquez, A., Gonzalez, H., & Haan, M. (2006). Dementia neuropsychiatric symptom severity, help-seeking patterns, and family caregiver unmet needs in the Sacramento Area Latino Study on Aging (SALSA). *Clinical gerontologist*, *29*(4), 1-15.
- Hinton, L., Franz, C., & Friend, J. (2004). Pathways to dementia diagnosis: Evidence for cross-ethnic differences. *Alzheimer Disease and Associated Disorders*, *18*(3), 134-144.
- Hinton, L., Franz, C. E., Reddy, G., Flores, Y., Kravitz, R. L., & Barker, J. C. (2007). Practice constraints, behavioral problems, and dementia care: primary care physicians' perspectives. *J Gen Intern Med*, *22*(11), 1487-1492.
- Hodgson, L. G., & Cutler, S. J. (2004). Help Seeking for Personal Concerns About Developing Alzheimer's Disease. *J Appl Gerontol*, *23*, 385-410.
- Hodgson, L. G., Cutler, S. J., & Livingston, K. (1999). Alzheimer's disease and symptom-seeking. *Am J Alzheimers Dis Other Demen*, *14*(6), 364-374.
- Hughes, T., Tyler, K., Danner, D., & Carter, A. (2009). African American caregivers: An exploration of pathways and barriers to a diagnosis of Alzheimer's disease for a family member with dementia. *Dementia*, *8*(95-116).
- Hurt, C. S., Burns, A., Brown, R. G., & Barrowclough, C. (2012). Why don't older adults with subjective memory complaints seek help? *Int J Geriatr Psychiatry*, *27*(4), 394-400.
- Innes, A., Szymczynska, P., & Stark, C. (2014). Dementia diagnosis and post-diagnostic support in Scottish rural communities: Experiences of people with dementia and their families. *Dementia*, *13*(2), 233-247.
- Janz, N. K., & Becker, M. H. (1984). The Health Belief Model: a decade later. *Health Educ Q*, *11*(1), 1-47.
- Jones, R. S., Chow, T. W., & Gatz, M. (2006). Asian Americans and Alzheimer's disease: Assimilation, culture, and beliefs. *Journal of Aging Studies*, *20*(1), 11-25.

- Juarez-Cedillo, T., Jarillo-Soto, E. C., & Rosas-Carrasco, O. (2014). Social Representation of Dementia and Its Influence on the Search for Early Care by Family Member Caregivers. *American Journal of Alzheimers Disease and Other Dementias*, 29(4), 344-353.
- Knudsen, L. V., Oberg, M., Nielsen, C., Naylor, G., & Kramer, S. E. (2010). Factors influencing help seeking, hearing aid uptake, hearing aid use and satisfaction with hearing aids: a review of the literature. *Trends Amplif*, 14(3), 127-154.
- Koch, L. H. (2006). Help-seeking behaviors of women with urinary incontinence: an integrative literature review. *J Midwifery Womens Health*, 51(6), e39-44.
- Koehn, S., McCleary, L., Garcia, L., Spence, M., Jarvis, P., & Drummond, N. (2012). Understanding Chinese–Canadian pathways to a diagnosis of dementia through a critical-constructionist lens. *Journal of Aging Studies*, 26(1), 44-54.
- Kotagal, V., Langa, K. M., Plassman, B. L., Fisher, G. G., Giordani, B. J., Wallace, R. B., . . . Foster, N. L. (2015). Factors associated with cognitive evaluations in the United States. *Neurology*, 84(1), 64-71.
- Leung, K. K., Finlay, J., Silvius, J. L., Koehn, S., McCleary, L., Cohen, C. A., . . . Drummond, N. (2011). Pathways to diagnosis: Exploring the experiences of problem recognition and obtaining a dementia diagnosis among Anglo-Canadians. *Health & Social Care in the Community*, 19(4), 372-381.
- Leventhal, H., Nerenz, D. R., & Steele, D. J. (1984). Illness representations and coping with health threats. In A. Baum, S. E. Taylor, & J. E. Singer (Eds.), *A Handbook of Psychology and Health, Volume IV: Social Psychological Aspects of Health* (pp. 219-252). New Jersey: Erlbaum.
- Levkoff, S., Levy, B., & Weitzman, P. F. (1999). The role of religion and ethnicity in the help seeking of family caregivers of elders with Alzheimer's disease and related disorders. *Journal of Cross-Cultural Gerontology*, 14(4), 335-356.
- Low, L. F., Anstey, K. J., Lackersteen, S. M. P., & Camit, M. (2011). Help-seeking and service use for dementia in Italian, Greek and Chinese Australians. *Aging & Mental Health*, 15(3), 397-404.
- McCleary, L., Persaud, M., Hum, S., Pimlott, N. J. G., Cohen, C. A., Koehn, S., . . . Drummond, N. (2013). Pathways to dementia diagnosis among South Asian Canadians. *Dementia*, 12(6), 769-789.
- McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Educ Q*, 15(4), 351-377.
- Mechanic, D. (1982). The epidemiology of illness behavior and its relationship to physical and psychological distress. In D. Mechanic (Ed.), *Symptoms, Illness Behavior, and Help-Seeking*. New Brunswick, NJ: Rutgers University Press.
- Millard, F., & Baune, B. (2009). Dementia - who cares? A comparison of community needs and primary care services. *Australian Family Physician*, 38(8), 642-+.
- Morgan, D. G., Walls-Ingram, S., Cammer, A., O'Connell, M. E., Crossley, M., Bello-Haas, V. D., . . . Stewart, N. (2014). Informal caregivers' hopes and expectations of a referral to a memory clinic. *Social Science & Medicine*, 102, 111-118.
- Morhardt, D., Pereyra, M., & Iris, M. (2010). Seeking a diagnosis for memory problems: the experiences of caregivers and families in 5 limited English proficiency communities. *Alzheimer Dis Assoc Disord*, 24 Suppl, S42-48.
- Mukadam, N., Cooper, C., Basit, B., & Livingston, G. (2011). Why do ethnic elders present later to UK dementia services? A qualitative study. *Int Psychogeriatr*, 23(7), 1070-1077.

- Mukadam, N., Cooper, C., & Livingston, G. (2011). A systematic review of ethnicity and pathways to care in dementia. *International Journal of Geriatric Psychiatry*, 26(1), 12-20.
- Mukadam, N., Waugh, A., Cooper, C., & Livingston, G. (2015). What would encourage help-seeking for memory problems among UK-based South Asians? A qualitative study. *BMJ Open*, 5(9), e007990.
- National Institute on Aging. (2014). Alzheimer's Disease Medications Fact Sheet. Retrieved from <http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-medications-fact-sheet>
- O'Mahony, M., & Hegarty, J. (2009). Help seeking for cancer symptoms: a review of the literature. *Oncol Nurs Forum*, 36(4), E178-184.
- Peterson, K., Hahn, H., Lee, A. J., Madison, C. A., & Atri, A. (2016). In the Information Age, do dementia caregivers get the information they need? Semi-structured interviews to determine informal caregivers' education needs, barriers, and preferences. *BMC Geriatr*, 16(1), 164.
- Phillipson, L., Magee, C., Jones, S., Reis, S., & Skaldzien, E. (2015). Dementia attitudes and help-seeking intentions: an investigation of responses to two scenarios of an experience of the early signs of dementia. *Aging Ment Health*, 19(11), 968-977.
- Pires, C., Silva, D., Maroco, J., Gino, S., Mendes, T., Schmand, B. A., . . . de Mendonca, A. (2012). Memory complaints associated with seeking clinical care. *Int J Alzheimers Dis*, 2012, 725329.
- Ploeg, J., Denton, M., Tindale, J., Hutchison, B., Brazil, K., Akhtar-Danesh, N., . . . Plenderleith, J. M. (2009). Older adults' awareness of community health and support services for dementia care. *Canadian Journal on Aging*, 28(4), 359-370.
- Qualls, S. H., Klebe, K. J., Berryman, K., Williams, A., Phillips, L., Layton, H., . . . Rogers, M. (2015). Motivational and cognitive pathways to medical help-seeking for Alzheimer's disease: a cognitive impairment response model. *J Gerontol B Psychol Sci Soc Sci*, 70(1), 57-66.
- Ramakers, I. H., Visser, P. J., Bittermann, A. J., Ponds, R. W., van Boxtel, M. P., & Verhey, F. R. (2009). Characteristics of help-seeking behaviour in subjects with subjective memory complaints at a memory clinic: a case-control study. *Int J Geriatr Psychiatry*, 24(2), 190-196.
- Relkin, N. (2000). Screening and early diagnosis of dementia. *Am J Manag Care*, 6(22 Suppl), S1111-1118; discussion S1119-1124.
- Rickwood, D., & Thomas, K. (2012). Conceptual measurement framework for help-seeking for mental health problems. *Psychol Res Behav Manag*, 5, 173-183.
- Samsi, K., Abley, C., Campbell, S., Keady, J., Manthorpe, J., Robinson, L., . . . Bond, J. (2014). Negotiating a Labyrinth: experiences of assessment and diagnostic journey in cognitive impairment and dementia. *International Journal of Geriatric Psychiatry*, 29(1), 58-67.
- Schrauf, R. W., & Iris, M. (2012). Very long pathways to diagnosis among African Americans and Hispanics with memory and behavioral problems associated with dementia. *Dementia*, 11(6), 743-763.
- Shaw, C. (2001). A review of the psychosocial predictors of help-seeking behaviour and impact on quality of life in people with urinary incontinence. *J Clin Nurs*, 10(1), 15-24.
- Sperling, R., Mormino, E., & Johnson, K. (2014). The evolution of preclinical Alzheimer's disease: implications for prevention trials. *Neuron*, 84(3), 608-622.

- Streams, M. E., Wackerbarth, S. B., & Maxwell, A. (2003). Diagnosis-seeking at subspecialty memory clinics: trigger events. *International Journal of Geriatric Psychiatry, 18*(10), 915-924.
- Wackerbarth, S. B., & Johnson, M. M. (2002). The carrot and the stick: benefits and barriers in getting a diagnosis. *Alzheimer Dis Assoc Disord, 16*(4), 213-220.
- Waldorff, F. B., Rishoj, S., & Waldemar, G. (2008). If you don't ask (about memory), they probably won't tell. *J Fam Pract, 57*(1), 41-44.
- Watari, K. F., & Gatz, M. (2004). Pathways to care for Alzheimer's disease among Korean Americans. *Cultur Divers Ethnic Minor Psychol, 10*(1), 23-38.
- Weimer, D. L., & Sager, M. A. (2009). Early identification and treatment of Alzheimer's disease: social and fiscal outcomes. *Alzheimers Dement, 5*(3), 215-226.
- Werner, P. (2003a). Factors influencing intentions to seek a cognitive status examination: a study based on the Health Belief Model. *Int J Geriatr Psychiatry, 18*(9), 787-794.
- Werner, P. (2003b). Knowledge about symptoms of Alzheimer's disease: Correlates and relationships to help-seeking behavior. *International Journal of Geriatric Psychiatry, 18*, 1029-1036.
- Werner, P. (2004a). Beliefs About Memory Problems and Help Seeking in Elderly Persons. *Clinical Gerontologist, 27*(4), 19-30.
- Werner, P. (2004b). Lay person's recommendations about interventions for Alzheimer's disease: Correlates and relationship to help-seeking behavior. *American Journal of Alzheimer's Disease and Other Dementias, 19*(5), 309-315.
- Werner, P. (2007). Family physicians' recommendations for help-seeking for a person with Alzheimer's disease. *Aging Clinical and Experimental Research, 19*(5), 356-363.
- Werner, P., Goldstein, D., Karpas, D. S., Chan, L., & Lai, C. (2014). Help-seeking for dementia: a systematic review of the literature. *Alzheimer Dis Assoc Disord, 28*(4), 299-310.
- Werner, P., & Heinik, J. (2004). Intentions of first-degree relatives of patients with Alzheimer's disease to seek a cognitive status examination. *International journal of geriatric psychiatry, 19*(5), 479-486.
- Werner, P., Heinik, J., Giveon, S., Segel-Karpas, D., & Kitai, E. (2014). Help-seeking preferences in the area of mild cognitive impairment: comparing family physicians and the lay public. *Clinical interventions in aging, 9*, 613.
- Werner, P., Heinik, J., & Kitai, E. (2013). Familiarity, knowledge, and preferences of family physicians regarding mild cognitive impairment. *International Psychogeriatrics, 25*(5), 805-813.
- Williams, C. L., Tappen, R. M., Rosselli, M., Keane, F., & Newlin, K. (2010). Willingness to be Screened and Tested for Cognitive Impairment: Cross-Cultural Comparison. *American Journal of Alzheimers Disease and Other Dementias, 25*(2), 160-166.
- World Health Organization. (2012). Dementia: A public health priority. Retrieved from [http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1)
- Zhao, M., Lv, X., Tuerxun, M., He, J., Luo, B., Chen, W., . . . Wang, H. (2015). Delayed help seeking behavior in dementia care: preliminary findings from the Clinical Pathway for Alzheimer's Disease in China (CPAD) study. *Int Psychogeriatr, 1*-9.

## CHAPTER 3

### **The Influence of Psychosocial and Cognitive Factors on Perceived Threat of Alzheimer's Disease Among a Representative Sample of U.S. Adults**

#### **Introduction**

Alzheimer's disease (AD) is among the most debilitating and prevalent diseases in the United States (Alzheimer's Association, 2016; Brookmeyer et al., 2011). In recent years, researchers, health care professionals, advocacy organizations, the media, as well as families and patients, have attempted to bring increased attention to the personal, social, and economic challenges posed by the disease. While there is currently no cure or proven strategy to prevent AD, methods are emerging to detect and diagnose early stages of the disease. These include the implementation of clinical criteria for diagnosing mild cognitive impairment (MCI) (Roberts, Karlawish, Uhlmann, Petersen, & Green, 2010), a precursor for AD, and the identification of blood, brain, and spinal fluid biomarkers that may help to detect prodromal stages of the disease before clinical manifestation occurs (Sperling, Mormino, & Johnson, 2014).

Future public health efforts to prevent or delay the onset and progression of AD may be heavily reliant on public support and participation in programs centered on early detection and diagnosis. Many organizations have emphasized the importance of early detection and diagnosis, pointing to potential benefits such as improved access to treatment and support services, greater autonomy of affected individuals in legal, financial, and care planning, and reduced health care costs. For instance, *Healthy People 2020* aims to increase AD diagnosis disclosure by 10 percent from a baseline of 34.8 percent of adults aged  $\geq 65$  with a dementia diagnosis (U.S. Department

of Health and Human Services & Office of Disease Prevention and Health Promotion), and the Alzheimer's Association and Centers for Disease Control and Prevention's (CDC) Healthy Brain Initiative calls for greater promotion of early detection and diagnosis (Alzheimer's Association and Centers for Disease Control and Prevention, 2013). These efforts include improving public awareness and knowledge about AD, educating health care providers about the importance of timely diagnosis and disclosure, and evaluating cognition during the Medicare Annual Wellness Visit (AWV) (Alzheimer's Association, 2015).

Perceived threat of AD potentially serves as a key factor in the likelihood of seeking timely diagnosis or participating in screening programs. Many individuals express a high level of perceived AD threat, especially those with a family history or personal experience (Blendon et al., 2012). Adult children of patients who have AD are more likely than those without a family history to engage "symptom-seeking behavior," in which they routinely check for signs of AD, opening the possibility for misinterpretation of a cognitive error as a disease symptom (L.G. Hodgson, Cutler, & Livingston, 1999). Among individuals who consult their physician about memory-related concerns, a significant proportion show no signs of cognitive impairment (Alladi, Arnold, Mitchell, Nestor, & Hodges, 2006). These individuals, who have been termed the "worried well," may also have heightened perceived AD threat, leading them to report memory changes and concerns to a doctor. Such individuals may also be at a heightened risk for misdiagnosis. In addition, a 3-year follow-up study of patients who sought help for memory complaints at an out-patient memory clinic found those individuals to have low conversion rates to MCI and dementia, and that memory complaints were significantly associated with psychosocial stress and feelings of anxiety (Elfgren, Gustafson, Vestberg, & Passant, 2010).

Thus, psychosocial factors may explain why individuals with no evidence of cognitive impairment may experience memory problems.

Despite progress in early detection of AD, the current emphasis on early diagnosis and screening may result in heightened perceived threat of AD, leading to overdiagnosis and overtreatment with adverse consequences for patients and families (Brunet et al., 2012; Le Couteur, Doust, Creasey, & Brayne, 2013). Because there are no preventive or curative treatments for AD, patients may try non-evidence-based therapies on the market (e.g., vitamin E, ginkgo biloba, cholinesterase inhibitors, etc.) potentially causing adverse and costly medical events (Le Couteur et al., 2013). There are also concerns about false positives and misdiagnosis, psychological distress and stigma associated with receiving an early AD diagnosis, and overburdening health care systems with increased diagnostic testing and screening (Le Couteur et al., 2013). Misdiagnosis of AD is a particularly salient issue as it could cause individuals and their families undue stress and anxiety, and put individuals at risk for unnecessary and costly treatments and health care actions. The flip side of these concerns is that low perceived AD threat may suppress help-seeking among cognitively impaired individuals in need of diagnosis, further widening disparities in health care and outcomes.

Relatively few studies have examined predictors of perceived AD threat. Those that exist focus mainly on individuals who may be genetically at risk for AD (e.g., first degree relatives) and/or have been conducted in small convenience samples with limited racial and ethnic diversity (Cutler & Hodgson, 1996; L. G. Hodgson & Cutler, 1997, 2003; Roberts & Connell, 2000; Suhr & Kinkela, 2007; Sun, Gao, & Coon, 2015). Several studies have been guided by health behavior theories and constructs, including the Health Belief Model (HBM) and the Common-Sense Model of Illness Representations (CSM), as well as models of health anxiety (L.

G. Hodgson & Cutler, 2003; Roberts & Connell, 2000; Suhr & Kinkela, 2007; Sun et al., 2015).

The HBM includes factors such as perceived threat, perceived benefits and barriers, self-efficacy, and cues to action, and has been largely successful in predicting a variety of health-related preventive and screening behaviors (Becker, 1974; Champion & Skinner, 2008; Janz & Becker, 1984). Within this framework, perceived threat has been defined as a combination of perceived susceptibility (i.e., belief about the likelihood of getting the disease) and perceived severity and concern (i.e., perceptions about the seriousness of getting the disease). The CSM has also been applied to many health conditions, and includes a variety of cognitive (identify, causes, consequences, and timeframe) and emotional processes that shape personal perceptions of a disease and may predict help-seeking behavior (Leventhal & Nerenz, 1985; Leventhal, Nerenz, & Steele, 1984).

In one of the most comprehensive studies of perceived AD threat to date, Suhr and Kinkela (2007) used social-cognitive theories of health anxiety to guide their investigation of predictors of perceived AD threat in 97 healthy older adults self-referred for community-wide memory screening. The models, proposed by Warwick and Salkovskis (1990) and Williams (2006) consider previous experience with an illness (e.g., observing the disease in a family member), as well as individual factors such as beliefs about the disease, anxiety, and selective attention to symptoms, to be important factors influencing worry about a disease or perceived threat. Suhr and Kinkela (2007) found significant relationships between perceived AD threat and several explanatory variables, including personal experience with AD (whether genetic or non-genetic), depression, and belief in negative age stereotypes. The authors also found that personal experience with AD moderated the relationship between actual cognitive performance and perceived AD threat. Participants with genetic AD experience (i.e., first or second degree



relative) had generally higher perceived threat when they had better cognitive performance, whereas those with non-genetic (e.g., spouse, friend, etc.) or no AD experience had higher perceived threat when they had worse cognitive performance. This suggests that personal experience with AD may play a particularly salient role in perceived AD threat and cognitive performance.

While the Suhr and Kinkela (2007) study provides valuable insight into predictors of perceived AD threat, the sample was relatively small and participants were “self-referred,” limiting the generalizability of the findings to the general aging population. The study also does not examine associations between self-reported or subjective memory complaints and perceived AD threat. Perceived AD threat is likely to be a response to a complex set of determinants, including knowledge and beliefs, family experience, psychological well-being, cognitive function, etc., and to our knowledge no studies to date have examined this complex set of factors in a large and diverse sample that is broadly representative of the U.S. adult population. Gaining a better understanding of potential factors related to perceived AD threat using a nationally representative sample of adults, with an emphasis on further delineating the role of family experience with AD, would provide useful information not only for assessing patients in clinical settings but for large-scale public health efforts aimed at early and accurate AD detection and diagnosis.

The aim of our study is to examine psychosocial and cognitive predictors of perceived AD threat, an understudied construct related to help-seeking behavior, among a nationally representative sample of U.S. adults. We were specifically interested in two questions: 1) What are the significant psychosocial and cognitive factors associated with perceived AD threat?; and 2) Does family experience with AD moderate the relationship between cognitive factors and

perceived threat? Based on prior research, we hypothesized that family experience with AD (Suhr & Kinkela, 2007), strong beliefs about genetic risk for AD (Hiraki, Chen, Roberts, Cupples, & Green, 2009), higher levels of depressive symptoms (L. G. Hodgson & Cutler, 1997; Suhr & Kinkela, 2007), poorer self-rated memory (Cutler & Hodgson, 1996), and lower objective cognitive functioning (Suhr & Kinkela, 2007), would be associated with higher perceived AD threat, and that family experience with AD would moderate the relationship between cognitive function and perceived AD threat (i.e., for those with family experience, lower objective cognitive function will be associated with greater perceived threat) (Suhr & Kinkela, 2007). We also hypothesized that those with greater knowledge about AD would have lower perceived AD threat (Werner, 2003). Finally, given the potential benefits of certain health behaviors in reducing the risk of cognitive decline and dementia, we wanted to examine the association between personal beliefs about the effectiveness of protective factors in lowering dementia risk (i.e. physical exercise, keeping mentally active, etc.) and perceived AD threat. To our knowledge, this is the first study to examine this association. Based on the notion that those who believe something can be done to reduce disease risk will feel less vulnerable, we hypothesized that people who have stronger beliefs that AD risk can be modified through health behaviors will have lower perceived AD threat.

## **Methods**

### ***Participants and Procedures***

Data for this project comes from the Health and Retirement Study (HRS), a longitudinal community-based cohort study with a nationally representative sample of over 30,000 individuals over the age of 50. The RAND enhanced version of public release data from the 2010

wave of the HRS study, including a brief supplementary survey module focused on knowledge and beliefs about AD, were used for this analysis (University of Michigan, 2010). A random subsample of individuals (n = 2,213) who participated in the 2010 HRS survey (n = 22,037) was invited to complete this ~3 minute module. Of the sampled respondents, 320 were determined ineligible for reasons of requiring proxy respondents, or current nursing home residency (sampling weights of 0). Among those who were eligible (n = 1,893), 1,840 individuals were Hispanic, non-Hispanic Black, and non-Hispanic White. Of these, 1,641 individuals completed the module and were included. We focused our analysis on respondents from these three racial/ethnic groups, given the small numbers of respondents in our sample from other backgrounds. The 1,641 respondents were compared to the larger HRS sample (excluding “other” race and those with sampling weights of 0), and no significant differences were found with regard to age, gender, education, and race/ethnicity. Complete details of the development, sampling and administration of the supplementary module have been published elsewhere (Roberts, McLaughlin, & Connell, 2014).

## ***Measures***

### *Demographics*

Demographic characteristics included age (recoded into 3 categories: 50-64 years, 65-74 years,  $\geq 75$  years), gender (male or female), race/ethnicity (recoded into 3 categories: Hispanic, non-Hispanic Black, and non-Hispanic White), marital status (married or single), and education (recoded into 3 categories: no degree, GED or high school diploma,  $\geq 2$ -year college degree).

Age was recoded into three categories to assess differences between age groups, as dementia risk substantially increases after age 65.

### *Perceived AD Threat*

Three items were used to examine perceived AD threat. Participants indicated their level of agreement (strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, and strongly disagree) with the following three statements: 1) “You would like to know your chances of someday getting Alzheimer’s,” 2) “You believe you will get Alzheimer’s someday,” and 3) “You worry about getting Alzheimer’s someday.” These items have been used in previous studies (Roberts & Connell, 2000). “Don’t know” responses (1.2-1.6% of responses across the three items) were folded into the “neither agree nor disagree” category. Items were reverse coded to aid model interpretability, and a composite mean score was calculated for each participant by averaging scores across the three items (Cronbach’s alpha of 0.635).

#### *Knowledge about AD*

Two previously validated items from the Alzheimer’s Disease Knowledge Scale (Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009) were chosen to assess understanding of AD risk and protective factors: 1) “Prescribed drugs that prevent Alzheimer’s disease are available” (True/False; correct answer = false), and “Having a parent or sibling with Alzheimer’s disease increases the chance of developing it” (True/False; correct answer = true). “Don’t know” responses were categorized as incorrect. A knowledge composite score was computed by summing the number of correct responses for each participant (with possible values of 0-2).

#### *Family Experience with AD*

Family experience with AD was assessed with two items. The first asks respondents: “Has your [husband/wife/partner], or a parent, sibling, or adult child of yours been diagnosed with Alzheimer’s?” (Yes/No). The second asks respondents “do you know someone who has had Alzheimer’s disease?” (Yes/No). Responses were recoded into three categories: 1=no experience, 2=knows someone, and 3=family experience.

### *Beliefs about AD Risk Factors*

Two items were used to examine beliefs about AD risk factors. Respondents were asked to rate on a 3-point scale how important (i.e., very, somewhat, or not at all) stress or genetics are in increasing a person's chances of getting Alzheimer's disease: 1) "Do you believe stress is very important, somewhat important, or not at all important in increasing a person's chances of getting Alzheimer's?" and 2) "Do you believe genetics is very important, somewhat important, or not at all important in increasing a person's chances of getting Alzheimer's?" "Don't know" responses (2.7-3.0% of responses across items) were categorized as not endorsing the belief. These items were treated as two separate ordinal variables in the regression model, and reverse coded to increase interpretability: 1=not at all important, 2=somewhat important, and 3=very important.

### *Beliefs about AD Protective Factors*

Four items assessed beliefs about AD protective factors. Respondents were asked how effective (i.e., very effective, somewhat effective, not at all effective) they believe four health behaviors are in lowering one's chances of getting AD: 1) keeping physically active, 2) keeping mentally active, 3) eating a healthy diet, 4) taking vitamins or dietary supplements. "Don't know" responses (1.3%-2.3% of responses across items) were categorized as not endorsing the behavior. Items were reverse coded to increase model interpretability (i.e., 1=not at all effective, 2=somewhat effective, and 3=very effective), and a composite score was generated by summing responses across the four items for each participant (Cronbach's alpha of 0.80). The composite measure had a score range from 4 to 12 with higher scores indicating stronger beliefs in the effectiveness of health behaviors in lowering risk for AD.

### *Symptoms of Depression*

Depression symptoms were assessed using a shortened version of the Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977), included in the HRS Core survey. The 2010 HRS measure of symptoms of depression consists of a subset of 8 items from the original 20-item CES-D scale and an additional item assessing respondents' level of energy. This shortened scale is commonly used in epidemiological studies to assess frequency of depressive symptoms, and has been previously established as having comparable reliability and validity to the 20-item CES-D scale (Steffick, 2000; Turvey, Wallace, & Herzog, 1999). We also chose to include the additional item "You had a lot of energy" as it is related to the construct of depression and has been found to load onto the common depression factor in factor analysis (Jones & Fonda, 2004). Respondents were asked to respond to the statements (response codes: 1 = Yes, 0 = No): 1) You felt depressed, 2) You felt that everything you did was an effort, 3) Your sleep was restless, 4) You were happy, 5) You felt lonely, 6) You enjoyed life, 7) You felt sad, 8) You could not get going, and 9) You had a lot of energy. "Don't know" responses (between 1 and 3 responses across items) were classified as not endorsing the statement. A composite score was created by reverse coding three positively worded items (i.e., You were happy, You enjoyed life, You had a lot of energy) and summing scores across the 9 items (Cronbach's alpha of 0.80). Higher scores indicate more depressive symptoms (range: 0-9).

### *Subjective Memory Complaints*

Subjective memory complaints were assessed using one item: "How would you rate your memory at the present time?" (on a 5-point scale: excellent, very good, good, fair, or poor). This measure is consistent with other studies that have examined subjective memory complaints in older adults (Paradise, Glozier, Naismith, Davenport, & Hickie, 2011).

### *Cognitive Function*

Cognitive function was assessed through the use of a cognition summary variable. The total cognition score sums the total recall and mental status indices in the HRS, and has a range of 0-35 with higher scores indicating better cognitive function (Fisher, Hassen, Rodgers, & Weir, 2013). The total recall index includes an immediate recall task (0-10) and a delayed recall task (0-10). The mental status index includes several tasks: serial 7s (0-5), backwards count from 20 (0-2), object naming—scissors or cactus (0-2), president naming (0-1), vice president naming (0-1), and date naming (0-4). Of the 1,641 respondents, 346 had missing data on the total cognition summary variable included in the RAND/HRS dataset. This was due to an age cut-off implemented in the HRS survey for reinterviewed respondents <65 years of age on specific mental status index items: date naming, object naming (scissors or cactus), and naming the president or vice president (Ofstedal, Fisher, & Hertzog, 2005). Under the assumption that respondents <65 years of age would have virtually no inaccuracies on these items, we imputed full accurate responses for these missing data points. A total cognition score was then re-computed by summing all mental status and total recall items.

The construct validity of the cognition measures and the consistency of the inter-relationships between individual items that compose the total cognition score have been previously demonstrated (Ofstedal et al., 2005). Factor analysis also supports the creation of a summary score. The total cognition score in this study had a Cronbach's alpha of 0.643, consistent with previous estimates for the HRS population (Ofstedal et al., 2005; Pertl, Lawlor, Robertson, Walsh, & Brennan, 2015).

### ***Data Analysis***

All analyses were conducted using SPSS version 22 software for Windows. Because the HRS uses a complex sampling design that involves clustering, stratification, and weights, the

SPSS Complex Samples module was used to account for sampling weights and other design elements.

Univariate descriptive analyses were conducted to characterize the sample in terms of demographics, including age, gender, race/ethnicity, education, etc., as well as cognitive and psychosocial variables of interest. Bivariate associations were explored through a series of chi-square and correlation analyses. Chi-square tests of association were performed to examine inter-relationships between categorical predictors, while a Pearson's *r* correlation matrix was generated to explore inter-relationships between ordinal predictors. Multicollinearity was assessed among independent variables by examining bivariate correlations. Cronbach's alpha statistics were computed for composite measures.

Linear regression models were fit to the data to examine predictors of perceived AD threat. Figures 3-1 and 3-2 show the conceptual models that were tested for each research question. A hierarchical approach to fitting the data was taken to assess the unique contributions of demographic, psychosocial and cognitive predictors. Demographic variables were modeled first (model 1), followed by psychosocial variables (model 2), and cognitive variables (model 3), with each subsequent model adjusting for variables in the previous models. The full model (model 3) contained 13 predictors: age (50-64, 65-74,  $\geq 75$ ), gender (male or female), race/ethnicity (Hispanic, non-Hispanic Black, and non-Hispanic White), education (No degree, GED or high school diploma,  $\geq 2$ -year college degree), marital status (married or single), AD knowledge, personal experience with AD (has spouse or first degree relative with AD, knows someone with AD but not a spouse or first degree relative, and no experience with AD), belief about stress as a risk factor, belief about genetics as a risk factor, beliefs about AD protective factors, depressive symptoms, subjective memory complaints, and cognitive function. Age was



entered into the model as a categorical variable for ease of interpretation and to assess differences between age groups, as dementia risk substantially increases after age 65. Interaction effects were also examined, including family experience as a possible moderator of the relationship between cognitive factors and perceived AD threat (model 4).

## **Results**

### ***Respondent Characteristics***

Demographic characteristics are summarized in Table 3-1. The mean age was 64.4 years, with most respondents under 75. The majority were non-Hispanic White (81.7%), followed by non-Hispanic Black (10.3%) and Hispanic (8.0%). Over half knew someone with AD who was not related (50.5%), while 13.3% had a spouse or first degree relative with AD.

The means, standard errors, and score ranges of psychosocial and cognitive variables are presented in Table 3-2. While most respondents correctly answered either one (43.3%) or both (42.8%) AD knowledge items, a considerable percentage (13.8%) still received an incorrect score on the two items. A high percentage saw genetics as a somewhat important or very important risk factor (90.7%), whereas just over half (58.7%) indicated that stress as a risk factor was somewhat or very important. The AD protective factors composite had a mean score of 9.1 (score range: 4-12), with respondents tending to believe that one could effectively lower one's chances of getting AD through specific health behaviors. Overall, respondents reported few depressive symptoms (mean = 1.64; range = 0-9 symptoms), and displayed relatively high cognitive function (mean = 23.3; range = 0-35). About a quarter rated their memory as poor (4.4%) or fair (18.5%). Over half (60%) wanted to know their chances of developing AD, 22.9% believed that they would someday have AD, and 29.4% worried about getting the disease.

### ***Exploratory Analysis of Perceived AD Threat***

Exploratory analyses on the three items used to examine perceived AD threat were conducted before creating a composite measure. All three items used to examine perceived concern about and susceptibility to AD were found to be significantly correlated at the 0.01 level (Pearson correlations were 0.281, 0.307, and 0.530). Multinomial logit models were used to further examine inter-relationships between the three variables and identify any nested relationships, however, these models did not reveal nested relationships between items. Additionally, we compared a linear regression model of the mean composite measure of perceived AD threat to a model of the item “You believe you will get Alzheimer’s someday” (5-point scale) to determine whether this “belief” measure drives the effects seen in the model of the composite measure, but we did not find evidence that this was the case (Table 3-3). Thus, a mean composite measure of the three items was used in the analyses in this paper. The composite measure of perceived AD threat was normally distributed with a mean of 2.87 (range = 1-5).

### ***Bivariate Summaries***

Tables 3-4 and 3-5 provide bivariate summaries of demographic, psychosocial, and cognitive predictors. As expected, the Chi-square test of associations showed significant relationships between several demographic variables, including age and education, age and marital status, age and race/ethnicity, gender and marital status, race/ethnicity and education, race/ethnicity and marital status, and education and marital status (Table 3-4). There were also significant relationships between personal experience with AD and race/ethnicity, as well as with education.

Pearson  $r$  correlations showed significant positive associations between perceived AD threat and stress as a risk factor, genetics as a risk factor, depressive symptoms, and subjective

memory complaints (Table 3-5). Cognitive function showed significant inverse relationships with subjective memory complaints and depressive symptoms, while there was a significant positive association between subjective memory complaints and depressive symptoms. In our assessment of multicollinearity, we did not find evidence of the independent variables being highly correlated. Pearson correlations ranged from -0.264 (stress as a risk factor and education level) to 0.417 (education level and cognitive function).

### ***Regression Analysis of Perceived AD Threat***

Table 3-6 presents the results of the linear regression analysis for the composite measure of perceived AD threat. The addition of psychosocial and cognitive variables produced a small improvement in the amount of variance explained across the models. In the full model (model 3), six predictors emerged as significantly associated with perceived AD threat. Compared to those aged 75 and over, perceived threat was significantly higher for respondents aged 50-64 and 65-74. Those with a family history of AD had significantly greater perceived threat than those with no experience. Stronger beliefs that stress or genetics are important AD risk factors were significantly associated with greater perceived threat. Higher perceived threat was significantly associated with having a greater number of depressive symptoms. Perceived AD threat was also significantly higher for those with poorer self-rated memory, and those with lower objectively measured cognitive function.

Two significant interaction effects were observed (model 4). First, personal experience with AD moderated the relationship between subjective memory complaints and perceived AD threat. The predicted increase in perceived AD threat associated with having subjective memory complaints was significantly greater for those who had a spouse or first degree relative with AD compared to those with no experience ( $B = 0.27, p < 0.01$ ). Second, personal experience with

AD moderated the relationship between age group and perceived AD threat. The predicted increase in perceived AD threat associated with being in the youngest age group (50-64) was significantly greater for those who had a spouse or first degree relative with AD compared to those with no experience ( $B = 0.55, p < 0.01$ ). The regression lines are graphed in Figures 3-3 and 3-4.

### **Discussion**

This study sought to explore psychosocial and cognitive predictors of perceived AD threat in a nationally representative sample of adults. The purpose was to gain insight into factors that influence perceived AD threat, an understudied construct that may predict who seeks out cognitive evaluation, and to inform clinical and public health efforts aimed at improving early and accurate diagnosis. Results from the multivariate linear regression analysis revealed significant relationships between perceived AD threat and age, personal experience with AD, beliefs about stress and genetics as AD risk factors, depressive symptoms, and subjective memory complaints, and cognitive function. Family experience with AD also played a significant moderating role in the relationship between subjective memory complaints and perceived AD threat. These findings suggest that among the general adult population, perceived AD threat is associated with a number of factors in addition to actual cognitive function. Personal beliefs, experiences, perceptions, and psychological well-being may underlie concerns and worries about AD.

As expected, several psychosocial factors were found to be significantly related to perceived AD threat, including personal experience with AD, depressive symptoms, and beliefs about stress and genetics as AD risk factors. The finding that personal experience with AD is

related to perceived AD threat is consistent with prior research (Suhr & Kinkela, 2007). We found that perceived AD threat was significantly greater for those with a family history of AD (e.g., spouse/partner, first degree relative) compared to those with no experience. The effect did not hold up for those who knew someone with AD but not a spouse or first-degree relative. This suggests that having a close family member with AD (whether genetically-related or not) may lead to heightened concerns about developing AD, whereas just knowing someone with AD may not confer the same effect. This likely reflects an awareness that family history and genetics are important contributors to AD risk. Those who have a close family member with AD may also experience more day-to-day contact with the person, or have taken on a caregiving role. In contrast to our study, Suhr and Kinkela (2007) conceived of personal experience as strictly genetic (i.e., first or second degree relative) or non-genetic (i.e., knowing someone not genetically related to them, including a spouse), and found that personal experience was significantly associated with perceived AD threat regardless of whether it was genetic or non-genetic. Slight differences in categorization of personal AD experience (i.e., spousal/partner relationships) may account for why our study did not also find a significant effect among those who knew someone with AD. Future research should determine whether the degree of personal closeness and contact with persons who have AD plays a role in perceived AD threat, above and beyond genetic relatedness.

Consistent with our hypotheses, having a greater number of depressive symptoms was significantly associated with higher perceived AD threat. Other studies have found similar associations between perceived AD threat and depressive symptoms (L. G. Hodgson & Cutler, 1997; Suhr & Kinkela, 2007) or distress symptoms related to AD experiences (Roberts, 2000; Roberts & Connell, 2000). Given that we cannot determine cause-effect relationships, we can

only speculate as to the reasons behind the observed association between perceived AD threat and depressive symptoms. One explanation is that depression itself can affect memory and cognition (Burt, Zembar, & Niederehe, 1995; Kindermann & Brown, 1997; Kizilbash, Vanderploeg, & Curtiss, 2002), which in turn may influence self-rated memory and perceived AD threat. Symptoms of depression often include forgetfulness, confusion, difficulty concentrating, and other cognitive or memory-related problems that could be misinterpreted as AD symptoms. Individuals with depression may be prone to a more ruminative style with more negative interpretations of memory concerns, and may also be more focused on current or future health issues (Marcus, Hughes, & Arnau, 2008). Another possible explanation is that personal concerns and worry about developing AD may lead to more depressive symptoms.

We also found significant associations between personal beliefs about risk factors for AD and perceived threat. As hypothesized, stronger endorsement of the importance of stress or genetics as risk factors were significantly associated with greater perceived threat. The fact that both genetic and psychosocial (i.e., stress) contributors to AD risk were strongly endorsed by respondents suggests an awareness that the disease isn't strictly genetically or environmentally determined, but that both factors are important. The association between these risk factor beliefs and heightened perceived AD threat may also indicate that respondents who strongly endorse genetics or stress as risk factors may feel they have less control over the disease and view it as less preventable, regardless of the fact that stress is potentially modifiable unlike genetics. Hiraki et al. (2009) also found that strong beliefs about genetics as an important risk factor was associated with higher perceived risk of AD, and attributed this finding to the fact that genetic disease is often viewed among the public as more severe and uncontrollable. Contrary to our hypothesis, we did not find a significant relationship between perceived AD threat and beliefs

about the effectiveness of AD protective factors, suggesting that having a greater openness to the efficacy of certain AD risk reduction methods does not significantly relate to or lessen concerns about AD.

Perceived AD threat was found to be significantly higher for those with poorer self-rated memory, and those with lower cognitive function. This is consistent with our hypothesis that individuals who perceive they have memory problems, or who have lower cognitive function, will also have greater concerns about AD. Cutler and Hodgson (1996) found a similar association between self-assessments of memory functioning and concerns about developing AD in a small sample of adult children with a living parent with probable AD and those with no family history. Specifically, negative assessments of memory functioning were associated with greater personal concerns about developing AD. Prior research has also found evidence that worse cognitive performance is significantly correlated with higher AD threat in individuals with non-genetic AD experience (Suhr & Kinkela, 2007). Similarly, we explored potential interaction effects of personal experience with AD on cognitive factors and perceived AD threat. We found a significant moderating effect of personal experience on subjective memory complaints and perceived threat, but not for objective cognitive function. The direction of this relationship suggests that those with a spouse or first degree relative with AD have higher perceived AD threat when they have more subjective memory complaints. One potential explanation for this is that the experience of having a close family member with AD may cause individuals to engage in more symptom-seeking behavior (L.G. Hodgson et al., 1999), leading to misinterpretation of cognitive errors and greater concerns about AD.

Age was the only demographic characteristic that was significantly associated with perceived AD threat in the multivariate linear model. Our findings revealed that perceived threat

was significantly greater for those aged 50-64 and 65-74 than for those 75 and over. Prior research has found associations between younger age and higher levels of perceived AD threat (Roberts & Connell, 2000; Suhr & Kinkela, 2007). This runs contrary to actual risk of AD, which increases with age. Nonetheless, younger individuals who are at or nearing age 65 may be more focused on future planning issues, and may feel particularly vulnerable given that disease onset typically occurs after this age. Those over 75 may be relieved they don't already have dementia, less anxious about the future, and more inclined to "let the chips fall where they may." There may also be possible cohort effects at play, as baby boomers tend to be more health-focused than the WWII generation preceding them. For instance, middle age adults are more likely to seek predictive genetic testing for AD than older adults (Roberts et al., 2004).

There are several limitations to the present study. First, to minimize participant burden, the HRS requires that experimental modules be kept brief (~3 minutes), necessitating the use of shortened scales for perceived AD threat and AD knowledge. In the case of AD knowledge, the two items used in this study were chosen to assess knowledge of certain risk and protective factors for AD, and may not reflect the full range of an individual's understanding or knowledge about Alzheimer's disease. Full scales would have allowed for a more in-depth examination of these factors with increased reliability of measures, and we recommend the use of full validated instruments in future studies (Carpenter et al., 2009; Roberts & Connell, 2000). Second, the supplemental survey module was administered in the 2010 wave of the HRS survey, which did not include a measure to assess help-seeking behavior for memory complaints. It was therefore not possible to examine the association between perceived AD threat and whether participants had sought help or intended to seek help for memory concerns. While the link between perceived threat and health behavior has a well-established theoretical and empirical basis, it would be



informative for future research to examine this association using a diverse and nationally representative sample. Third, the cross-sectional nature of this study did not allow us to investigate causality (all findings were correlational) or examine variable relationships across time. Future studies should take a longitudinal approach to further examine predictors of perceived AD threat, as well as the relationship between perceived AD threat and help-seeking intentions or behavior. Lastly, respondents requiring proxy interviews were not included in the study sample, potentially raising the likelihood of selection bias. In the HRS, proxy interviews are obtained for participants who cannot self-respond due to cognitive or physical limitations (Ofstedal et al., 2005). A different set of measures is used to assess a respondent's cognitive status in proxy interviews. Because poor cognitive function is a reason for proxy interviews, we may be selecting for individuals with higher levels of cognitive function while excluding respondents with more severe cognitive impairment. Thus, our study sample may not be fully representative of the older population given that people with more severe cognitive impairment may be underrepresented.

Despite these limitations, to our knowledge this is the first study of perceived AD threat using nationally representative data from a large and diverse sample of participants. As the prevalence of AD rises in the U.S. over the coming years, more people will have personal experience with a family member who has the disease. As this happens, public awareness and concerns about AD will also grow, as will public interest in early diagnostic testing. Therefore, there is a need to understand perceived AD threat in the general aging population. As the findings of this study suggest, perceived AD threat is not just a function of an individual's cognitive impairment, but a response to a complex set of determinants that include personal beliefs and experiences, and psychological well-being. In the current absence of effective ways

to prevent and treat AD, educational efforts focused on AD awareness, knowledge and beliefs among patients, health care providers, and the public will become increasingly important in preventing overdiagnosis and overtreatment of the disease.

Information about factors likely to drive help-seeking behavior for AD concerns will be particularly helpful for formulating diagnostic guidelines and practices among health care professionals. For instance, our finding that family experience moderates the association between self-rated memory and perceived threat, but not objective cognitive function, highlights the need for careful initial cognitive screening of individuals who present with memory complaints, which includes objective measures of cognitive functioning and informant history. There are many causes of cognitive difficulties, and patients and health care providers need to be educated about non-dementia factors that can influence subjective memory perceptions and objective cognitive function. Factors such as family experience with AD and depressive symptoms should be taken into consideration during patient visits. Future research should focus on further delineating the relationships between perceived AD threat and family experience, as well as its role in help-seeking behavior.

**Table 3-1: HRS Population Characteristics (N = 1,641)**

<b>characteristics</b>	<b>n</b>	<b>weighted % (se) or mean (se)</b>
<b>Age</b>		<b>64.4 (0.4), range: 50-99</b>
50-64	782	57.6 (1.6)
65-74	456	24.3 (1.2)
75 and over	403	18.1 (1.3)
<b>Female</b>	917	53.6 (1.7)
<b>Race and ethnicity</b>		
Hispanic	212	8.0 (1.0)
Non-Hispanic Black	312	10.3 (1.0)
Non-Hispanic White	1117	81.7 (1.4)
<b>Education</b>		
No degree	311	12.6 (1.1)
GED or high school diploma	889	53.4 (1.9)
≥ 2-year college degree	441	34.0 (2.0)
<b>Married</b>	981	62.2 (1.5)
<b>Personal experience with AD</b>		
Has a spouse or first degree relative with AD	212	13.3 (1.1)
Knows someone with AD but not a spouse or first degree relative	807	50.5 (1.6)
No experience with AD	622	36.2 (1.5)

Percentages and estimates are weighted.

**Table 3-2: Means, SE, and Score Range of Psychosocial and Cognitive Variables (N = 1,641)**

<b>Variables</b>	<b>Mean</b>	<b>SE</b>	<b>Score range (interpretation)</b>
AD knowledge ( <i>composite</i> )	1.29	0.03	0-2 (number correct) 0 = 13.8% 1 = 43.3% 2 = 42.8%
Personal experience	2.23	0.02	1-3 1 = spouse or relative with AD (13.3%) 2 = knows someone (50.5%) 3 = no experience (36.2%)
Stress as a risk factor	1.79	0.03	1-3 1 = not at all important (41.3%) 2 = somewhat important (38.2%) 3 = very important (20.5%)
Genetics as a risk factor	2.42	0.03	1-3 1 = not at all important (9.3%) 2 = somewhat important (39.4%) 3 = very important (51.3%)
AD protective factors ( <i>composite</i> )	9.1	0.08	4-12 (not at all effective to very effective)
Depressive symptoms ( <i>composite</i> )	1.64	0.07	0-9 (number of symptoms)
Subjective memory complaints	2.84	0.03	1-5 (memory rating) 1 = excellent (7.0%) 2 = very good (29.5%) 3 = good (40.6%) 4 = fair (18.5%) 5 = poor (4.4%)
Cognitive function ( <i>composite</i> )	23.3	0.15	0-35 (low to high functioning)
Perceived threat of AD ( <i>composite</i> )	2.87	0.03	1-5 (low to high perceived threat)

---

Mean and SE estimates are weighted

**Table 3-3:** Comparison of Linear Regression Results for Mean Composite Measure of Perceived AD Threat and “You believe you will get AD someday” (N = 1,625)

Variables	Full Model of Mean Composite Measure of Perceived Threat†	Full Model of "You believe you will get AD someday"††
	B [95% CI]	B [95% CI]
<b>Age</b>		
50-64	<b>0.40*** [0.22, 0.57]</b>	<b>0.36** [0.16, 0.56]</b>
65-74	<b>0.16* [0.01, 0.32]</b>	0.14 [-0.05, 0.33]
75 and over (ref)	0.00	0.00
<b>Female</b>	0.02 [-0.10, 0.14]	-0.06 [-0.20, 0.08]
<b>Race/Ethnicity</b>		
Hispanic	0.11 [-0.10, 0.31]	-0.02 [-0.35, 0.31]
Non-Hispanic Black	<b>-0.17 [-0.37, 0.03]</b>	<b>-0.22* [-0.43, -0.01]</b>
Non-Hispanic White (ref)	0.00	0.00
<b>Education</b>		
No degree	-0.06 [-0.26, 0.14]	0.03 [-0.23, 0.28]
GED or high school diploma	-0.11 [-0.26, 0.03]	-0.09 [-0.27, 0.09]
≥ 2-year college degree (ref)	0.00	0.00
<b>Married</b>	0.09 [-0.06, 0.25]	0.10 [-0.05, 0.25]
<b>AD Knowledge</b>	0.05 [-0.05, 0.15]	0.05 [-0.05, 0.15]
<b>Personal Experience</b>		
Has a spouse or first degree relative with AD	<b>0.55*** [0.37, 0.72]</b>	<b>0.56*** [0.35, 0.78]</b>
Knows someone with AD but not a spouse or first degree relative	0.13 [-0.01, 0.26]	0.09 [-0.05, 0.23]
No experience with AD (ref)	0.00	0.00
<b>Stress as a Risk Factor</b>	<b>0.11** [0.04, 0.19]</b>	<b>0.18** [0.07, 0.28]</b>
<b>Genetics as a Risk Factor</b>	<b>0.12** [0.04, 0.20]</b>	0.24 [-0.09, 0.14]
<b>Beliefs about AD Protective Factors</b>	0.01 [-0.03, 0.04]	-0.02 [-0.05, 0.01]
<b>Depressive Symptoms</b>	<b>0.05** [0.02, 0.08]</b>	<b>0.06** [0.02, 0.10]</b>
<b>Subjective Memory Complaints</b>	<b>0.09** [0.03, 0.15]</b>	<b>0.12** [0.04, 0.20]</b>
<b>Cognitive Function</b>	<b>-0.02** [-0.03, -0.01]</b>	<b>-0.03* [-0.04, -0.01]</b>
<b>Constant</b>	<b>1.89*** [1.47, 2.31]</b>	<b>2.06*** [1.43, 2.70]</b>
<b>R<sup>2</sup></b>	0.114	0.095

Data are weighted. There were between 2 to 9 missing data points across several items, reflected in reduced sample size in model.

\*\*\*p<0.001; \*\*p < 0.01; \*p < 0.05.

†Dependent variable: Perceived AD threat mean composite (1 = strongly disagree to 5 = strongly agree; low to high perceived threat).

††Dependent variable: "You believe you will get Alzheimer's someday" (5-point scale; 1 = strongly disagree to 5 = strongly agree; low to high perceived threat).

SMCs = subjective memory complaints

**Table 3-4: Bivariate Summary of Associations Among Categorical Predictors of Perceived AD Threat (Chi-square tests of association; N = 1,641)**

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>
<b>1. Age (categorical)</b>	—								
<b>2. Gender</b>	$\chi^2$ (1.72, 94.84) = 0.17 $p = 0.920$	—							
<b>3. Race/Ethnicity</b>	$\chi^2$ (3.37, 185.35) = 16.44 $p = 0.019$	$\chi^2$ (1.83, 100.41) = 5.06 $p = 0.170$	—						
<b>4. Education</b>	$\chi^2$ (3.66, 201.37) = 72.25 $p < 0.001$	$\chi^2$ (1.71, 94.16) = 6.57 $p = 0.187$	$\chi^2$ (2.97, 163.50) = 152.90 $p < 0.001$	—					
<b>5. Marital Status</b>	$\chi^2$ (1.71, 93.80) = 61.73 $p < 0.001$	$\chi^2$ (1, 55) = 53.21 $p < 0.001$	$\chi^2$ (1.82, 100.15) = 62.76 $p < 0.001$	$\chi^2$ (1.61, 88.73) = 39.15 $p < 0.001$	—				
<b>6. Personal Experience</b>	$\chi^2$ (3.49, 191.77) = 6.43 $p = 0.313$	$\chi^2$ (1.94, 106.72) = 2.62 $p = 0.427$	$\chi^2$ (3.22, 177.09) = 19.79 $p = 0.006$	$\chi^2$ (3.07, 169.04) = 25.96 $p = 0.012$	$\chi^2$ (1.97, 108.17) = 10.08 $p = 0.050$	—			
<b>7. Want to know AD risk (1-5)</b>	$\chi^2$ (6.71, 368.98) = 58.56 $p < 0.001$	$\chi^2$ (3.68, 202.22) = 1.37 $p = 0.932$	$\chi^2$ (6.00, 329.99) = 25.00 $p = 0.010$	$\chi^2$ (6.76, 371.83) = 22.93 $p = 0.067$	$\chi^2$ (3.64, 199.92) = 19.19 $p = 0.032$	$\chi^2$ (6.22, 342.01) = 26.51 $p = 0.058$	—		
<b>8. Believe will get AD (1-5)</b>	$\chi^2$ (6.75, 371.39) = 22.76 $p = 0.029$	$\chi^2$ (3.57, 196.29) = 2.83 $p = 0.77$	$\chi^2$ (6.56, 361.04) = 46.12 $p < 0.001$	$\chi^2$ (6.71, 368.79) = 64.55 $p < 0.001$	$\chi^2$ (3.57, 196.39) = 20.60 $p = 0.048$	$\chi^2$ (6.63, 364.50) = 65.77 $p < 0.001$	$\chi^2$ (10.31, 567.25) = 255.89 $p < 0.001$	—	
<b>9. Worry about getting AD (1-5)</b>	$\chi^2$ (6.31, 347.30) = 29.79 $p = 0.006$	$\chi^2$ (3.78, 208.01) = 10.81 $p = 0.195$	$\chi^2$ (6.07, 333.56) = 26.55 $p = 0.011$	$\chi^2$ (6.17, 339.39) = 29.41 $p = 0.084$	$\chi^2$ (3.74, 205.84) = 4.94 $p = 0.594$	$\chi^2$ (6.81, 374.29) = 63.78 $p < 0.001$	$\chi^2$ (9.85, 541.59) = 194.72 $p < 0.001$	$\chi^2$ (11.54, 634.74) = 755.03 $p < 0.001$	—

Data are weighted.

Includes Rao-Scott F adjusted chi-square statistic and Satterthwaite approximation for degrees of freedom.

**Table 3-5:** Bivariate Summary with Pearson Correlations for Perceived AD Threat and Psychosocial and Cognitive Predictors (N = 1,641)

	1	2	3	4	5	6	7	8	9	10	11
1. AD Knowledge (0-2)	—										
2. Stress as a Risk Factor (1-3)	<b>-0.116**</b>	—									
3. Genetics as a Risk Factor (1-3)	<b>0.294**</b>	<b>0.143**</b>	—								
4. AD Protective Factors (4-12)	<b>-0.081**</b>	<b>0.276**</b>	<b>0.111**</b>	—							
5. Depressive Symptoms (0-9)	<b>-0.096**</b>	<b>0.115**</b>	0.036	-0.029	—						
6. SMCs (1-5)	-0.040	<b>0.116**</b>	-0.022	-0.037	<b>0.277**</b>	—					
7. Cognitive Function (0-35)	<b>0.274**</b>	<b>-0.227**</b>	<b>0.080**</b>	-0.021	<b>-0.181**</b>	<b>-0.251**</b>	—				
8. Perceived threat of AD (1-5)	0.038	<b>0.127**</b>	<b>0.154**</b>	0.015	<b>0.170**</b>	<b>0.127**</b>	-0.043	—			
9. Want to know AD risk (1-5)	0.029	0.045	<b>0.176**</b>	0.039	<b>0.056*</b>	0.003	<b>0.055*</b>	<b>0.705*</b>	—		
10. Believe will get AD (1-5)	0.036	<b>0.137**</b>	<b>0.069**</b>	-0.046	<b>0.165**</b>	<b>0.151**</b>	<b>-0.098**</b>	<b>0.783**</b>	<b>0.307**</b>	—	
11. Worry about getting AD (1-5)	0.026	<b>0.111**</b>	<b>0.101**</b>	0.031	<b>0.165**</b>	<b>0.138**</b>	<b>-0.060*</b>	<b>0.800**</b>	<b>0.281**</b>	<b>0.530**</b>	—

Data are unweighted.

**\*\*p < 0.01; \*p < 0.05.**

SMCs: subjective memory complaints

**Table 3-6:** Summary of Linear Regression Analysis of Perceived AD Threat (N= 1,625)

Variables	Model 1	Model 2	Model 3	Model 4 (Interaction Effects)
	B [95% CI]	B [95% CI]	B [95% CI]	B [95% CI]
<b>Age</b>				
[1] 50-64	<b>0.37*** [0.22, 0.52]</b>	<b>0.31*** [0.15, 0.47]</b>	<b>0.40*** [0.22, 0.57]</b>	0.25 [-0.02, 0.51]
[2] 65-74	<b>0.16* [0.01, 0.30]</b>	0.12 [-0.04, 0.27]	<b>0.16* [0.01, 0.32]</b>	0.12 [-0.16, 0.41]
[3] 75 and over (ref)	0.00	0.00	0.00	0.00
<b>Female</b>				
	0.04 [-0.08, 0.17]	0.01 [-0.12, 0.13]	0.02 [-0.10, 0.14]	0.02 [-0.10, 0.14]
<b>Race/Ethnicity</b>				
Hispanic	0.16 [-0.04, 0.35]	0.14 [-0.06, 0.33]	0.11 [-0.10, 0.31]	0.10 [-0.11, 0.32]
Non-Hispanic Black	-0.12 [-0.31, 0.08]	-0.12 [-0.32, 0.08]	-0.17 [-0.37, 0.03]	-0.16 [-0.36, 0.04]
Non-Hispanic White (ref)	0.00	0.00	0.00	0.00
<b>Education</b>				
No degree	0.11 [-0.09, 0.31]	0.05 [-0.16, 0.26]	-0.06 [-0.26, 0.14]	-0.05 [-0.25, 0.14]
GED or high school diploma	-0.04 [-0.18, 0.10]	-0.06 [-0.21, 0.08]	-0.11 [-0.26, 0.03]	-0.11 [-0.26, 0.03]
≥ 2-year college degree (ref)	0.00	0.00	0.00	0.00
<b>Married</b>				
	0.02 [-0.15, 0.19]	0.10 [-0.06, 0.25]	0.09 [-0.06, 0.25]	0.09 [-0.06, 0.24]
<b>AD Knowledge</b>				
		0.04 [-0.05, 0.13]	0.05 [-0.05, 0.15]	0.05 [-0.04, 0.15]
<b>Personal Experience</b>				
[1] Has a spouse or first degree relative with AD		<b>0.55*** [0.37, 0.72]</b>	<b>0.55*** [0.37, 0.72]</b>	<b>-0.67* [-1.33, -0.002]</b>
[2] Knows someone with AD but not a spouse or first degree relative		0.11 [-0.02, 0.24]	0.13 [-0.01, 0.26]	-0.31 [-0.82, 0.20]
[3] No experience with AD (ref)		0.00	0.00	0.00
<b>Stress as a Risk Factor</b>				
		<b>0.13** [0.05, 0.20]</b>	<b>0.11** [0.04, 0.19]</b>	<b>0.11** [0.04, 0.19]</b>
<b>Genetics as a Risk Factor</b>				
		<b>0.12** [0.04, 0.20]</b>	<b>0.12** [0.04, 0.20]</b>	<b>0.12** [0.04, 0.20]</b>
<b>Beliefs about AD Protective Factors</b>				
		0.01 [-0.03, 0.04]	0.01 [-0.03, 0.04]	0.01 [-0.02, 0.04]
<b>Depressive Symptoms</b>				
		<b>0.06*** [0.03, 0.10]</b>	<b>0.05** [0.02, 0.08]</b>	<b>0.05** [0.02, 0.08]</b>
<b>Subjective Memory Complaints</b>				
			<b>0.09** [0.03, 0.15]</b>	0.004 [-0.11, 0.11]



<b>Cognitive Function</b>				<b>-0.02**</b> [-0.03, -0.01]	<b>-0.02**</b> [-0.03, -0.004]
†Personal Exp[1] x SMCs					<b>0.27**</b> [0.10, 0.45]
†Personal Exp[2] x SMCs					0.11 [-0.03, 0.26]
††Personal Exp[1] x Age[1]					<b>0.55**</b> [0.17, 0.93]
††Personal Exp[2] x Age[1]					0.19 [-0.12, 0.49]
†††Personal Exp[1] x Age[2]					0.33 [-0.12, 0.77]
†††Personal Exp[2] x Age[2]					0.01 [-0.36, 0.38]
<b>Constant</b>	<b>2.59***</b> [2.42, 2.76]	<b>1.77***</b> [1.43, 2.11]	<b>1.89***</b> [1.47, 2.31]	<b>2.20***</b> [1.73, 2.67]	
<b>R<sup>2</sup></b>	0.030	0.103	0.114	0.123	

Data are weighted. There were between 2 to 9 missing data points across several items, reflected in reduced sample size in model.

\*\*\* $p < 0.001$ ; \*\* $p < 0.01$ ; \* $p < 0.05$ .

Dependent variable: Perceived AD threat composite (1 = strongly disagree to 5 = strongly agree; low to high perceived threat).

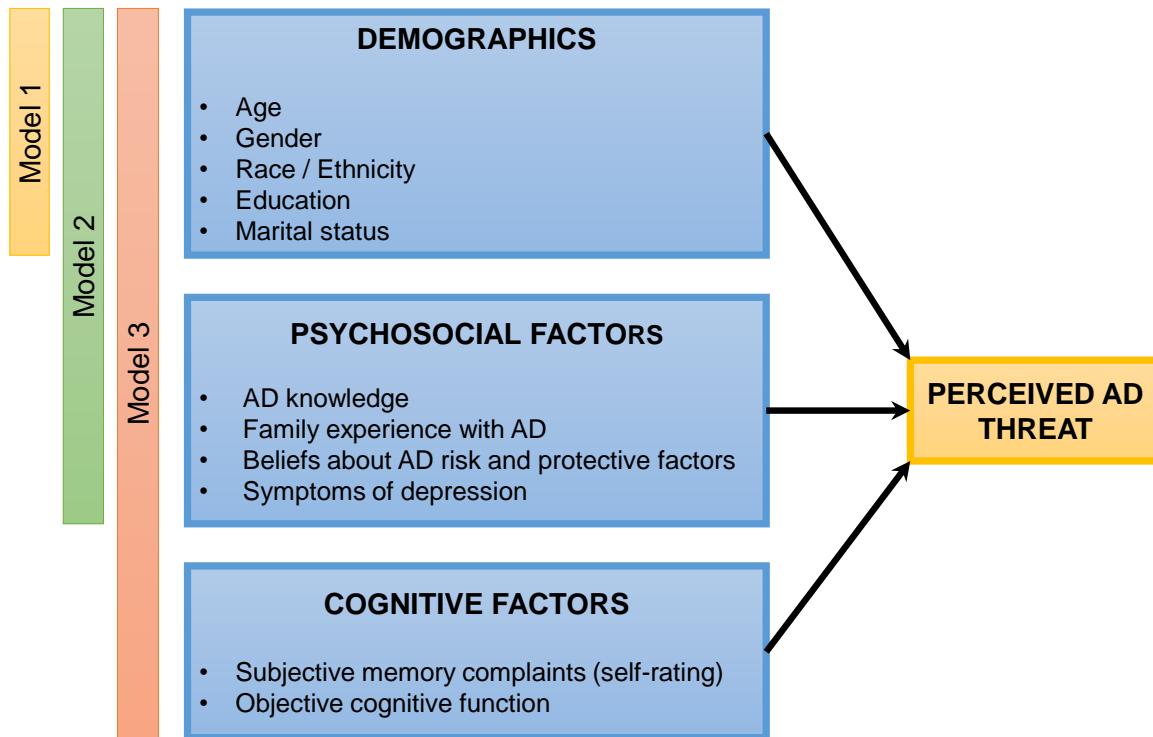
SMCs = subjective memory complaints

†Reference category = Personal Experience [3] x SMCs

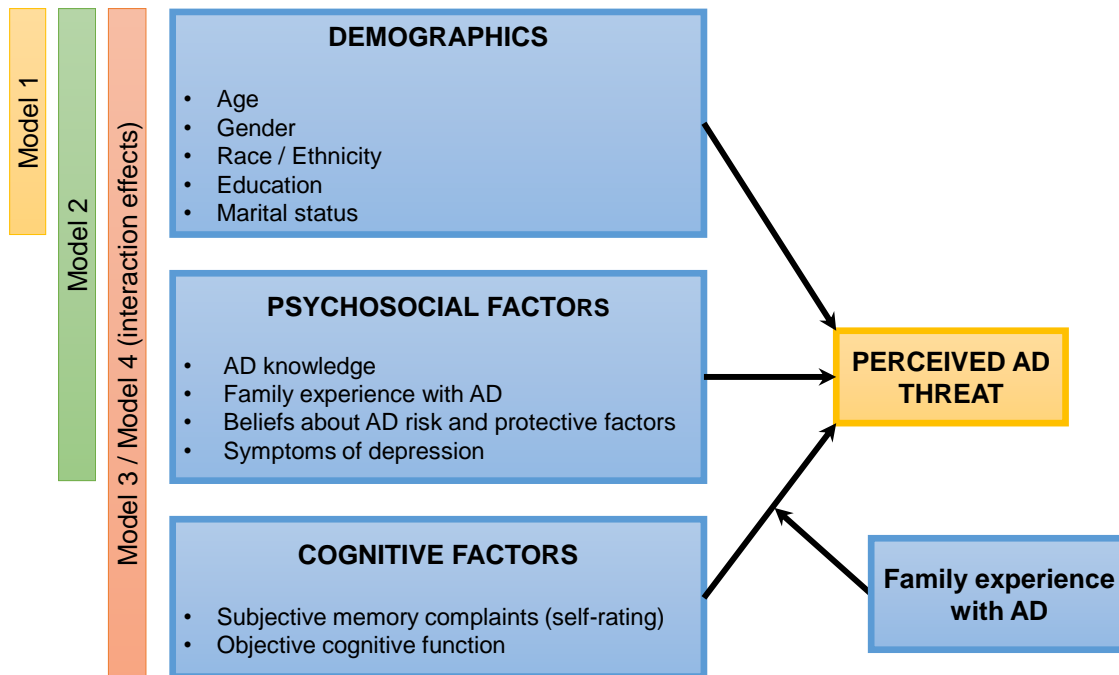
††Reference category = Personal Experience [3] x Age category [3]

†††Reference category = Personal Experience [3] x Age category [3]

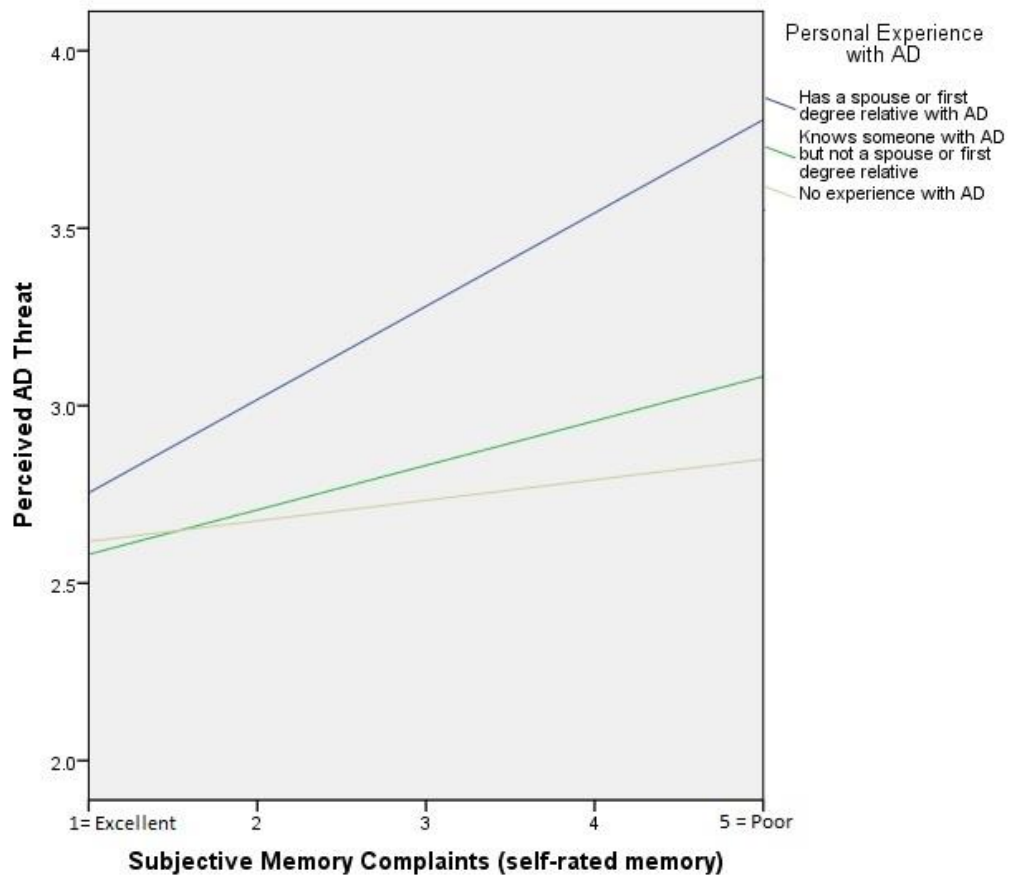
**Figure 3-1:** Conceptual Model of Research Question 1: What are the significant psychosocial and cognitive factors associated with perceived AD threat?



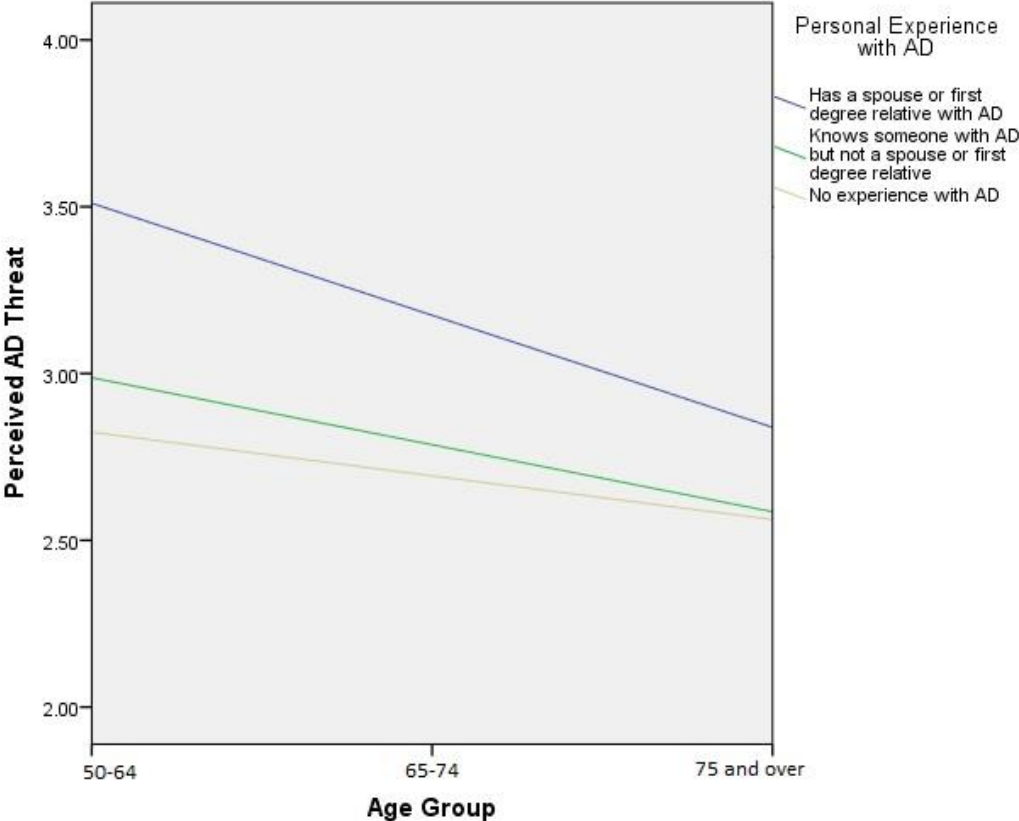
**Figure 3-2:** Conceptual Model of Research Question 2: Does family experience with AD moderate the relationship between cognitive factors and perceived AD threat?



**Figure 3-3:** Moderating effect of personal experience with AD on the relationship between subjective memory complaints and perceived AD threat



**Figure 3-4:** Moderating effect of personal experience with AD on the relationship between age group and perceived AD threat



## References

- Alladi, S., Arnold, R., Mitchell, J., Nestor, P. J., & Hodges, J. R. (2006). Mild cognitive impairment: applicability of research criteria in a memory clinic and characterization of cognitive profile. *Psychol Med*, 36(4), 507-515.
- Alzheimer's Association. (2015). Policy Brief: Early Detection and Diagnosis. Retrieved from <http://www.alz.org/publichealth/downloads/policy-brief.pdf>
- Alzheimer's Association. (2016). 2016 Alzheimer's Disease Facts and Figures. Retrieved from [http://www.alz.org/documents\\_custom/2016-facts-and-figures.pdf](http://www.alz.org/documents_custom/2016-facts-and-figures.pdf)
- Alzheimer's Association and Centers for Disease Control and Prevention. (2013). *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*. Retrieved from <http://www.alz.org/publichealth/downloads/2013-RoadMap.pdf>
- Becker, M. H. (1974). The Health Belief Model and Personal Health Behavior. *Health Education Monographs*, 2, 324-473.
- Blendon, R. J., Benson, J. M., Wikler, E. M., Weldon, K. J., Georges, J., Baumgart, M., & Kallmyer, B. A. (2012). The Impact of Experience with a Family Member with Alzheimer's Disease on Views about the Disease across Five Countries. *Int J Alzheimers Dis*, 2012, 903645.
- Brookmeyer, R., Evans, D. A., Hebert, L., Langa, K. M., Heeringa, S. G., Plassman, B. L., & Kukull, W. A. (2011). National estimates of the prevalence of Alzheimer's disease in the United States. *Alzheimers Dement*, 7(1), 61-73.
- Brunet, M. D., McCartney, M., Heath, I., Tomlinson, J., Gordon, P., Cosgrove, J., . . . Bhattia, N. (2012). There is no evidence base for proposed dementia screening. *BMJ*, 345, e8588.
- Burt, D. B., Zembar, M. J., & Niederehe, G. (1995). Depression and memory impairment: a meta-analysis of the association, its pattern, and specificity. *Psychol Bull*, 117(2), 285-305.
- Carpenter, B. D., Balsis, S., Otilingam, P. G., Hanson, P. K., & Gatz, M. (2009). The Alzheimer's Disease Knowledge Scale: development and psychometric properties. *Gerontologist*, 49(2), 236-247.
- Champion, V. L., & Skinner, C. S. (2008). The Health Belief Model. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health Behavior and Health Education* (pp. 45-62). San Francisco, CA.
- Cutler, S. J., & Hodgson, L. G. (1996). Anticipatory dementia: a link between memory appraisals and concerns about developing Alzheimer's disease. *Gerontologist*, 36(5), 657-664.
- Elfgrén, C., Gustafson, L., Vestberg, S., & Passant, U. (2010). Subjective memory complaints, neuropsychological performance and psychiatric variables in memory clinic attendees: a 3-year follow-up study. *Arch Gerontol Geriatr*, 51(3), e110-114.
- Fisher, G. G., Hassen, H., Rodgers, W. L., & Weir, D. R. (2013). Health and Retirement Study Imputation of Cognitive Functioning Measures: 1992-2010. Retrieved from <http://hrsonline.isr.umich.edu/modules/meta/xyear/cogimp/desc/COGIMPdd.pdf>
- Hiraki, S., Chen, C. A., Roberts, J. S., Cupples, L. A., & Green, R. C. (2009). Perceptions of familial risk in those seeking a genetic risk assessment for Alzheimer's disease. *J Genet Couns*, 18(2), 130-136.
- Hodgson, L. G., & Cutler, S. J. (1997). Anticipatory dementia and well-being. *Am J Alzheimers Dis Other Dement*, 12, 62-66.

- Hodgson, L. G., & Cutler, S. J. (2003). Looking for signs of Alzheimer's disease. *Int J Aging Hum Dev*, 56(4), 323-343.
- Hodgson, L. G., Cutler, S. J., & Livingston, K. (1999). Alzheimer's disease and symptom-seeking. *Am J Alzheimers Dis Other Demen*, 14(6), 364-374.
- Janz, N. K., & Becker, M. H. (1984). The Health Belief Model: a decade later. *Health Educ Q*, 11(1), 1-47.
- Jones, R. N., & Fonda, S. J. (2004). Use of an IRT-based latent variable model to link different forms of the CES-D from the Health and Retirement Study. *Soc Psychiatry Psychiatr Epidemiol*, 39(10), 828-835.
- Kindermann, S. S., & Brown, G. G. (1997). Depression and memory in the elderly: a meta-analysis. *J Clin Exp Neuropsychol*, 19(5), 625-642.
- Kizilbash, A. H., Vanderploeg, R. D., & Curtiss, G. (2002). The effects of depression and anxiety on memory performance. *Arch Clin Neuropsychol*, 17(1), 57-67.
- Le Couteur, D. G., Doust, J., Creasey, H., & Brayne, C. (2013). Political drive to screen for pre-dementia: not evidence based and ignores the harms of diagnosis. *BMJ*, 347, f5125.
- Leventhal, H., & Nerenz, D. (1985). The assessment of illness cognition. In P. Korely (Ed.), *Measurement Strategies in Health Psychology* (pp. 517-554). New York: Wiley.
- Leventhal, H., Nerenz, D. R., & Steele, D. J. (1984). Illness representations and coping with health threats. In A. Baum, S. E. Taylor, & J. E. Singer (Eds.), *A Handbook of Psychology and Health, Volume IV: Social Psychological Aspects of Health* (pp. 219-252). New Jersey: Erlbaum.
- Marcus, D. K., Hughes, K. T., & Arnau, R. C. (2008). Health anxiety, rumination, and negative affect: a mediational analysis. *J Psychosom Res*, 64(5), 495-501.
- Ofstedal, M. B., Fisher, G. G., & Hertzog, A. R. (2005). HRS/AHEAD documentation report: Documentation of cognitive functioning measures in the Health and Retirement Study. Retrieved from the Survey Research Center at the Institute for Social Research, University of Michigan. <http://hrsonline.isr.umich.edu/sitedocs/userg/dr-006.pdf>
- Paradise, M. B., Glozier, N. S., Naismith, S. L., Davenport, T. A., & Hickie, I. B. (2011). Subjective memory complaints, vascular risk factors and psychological distress in the middle-aged: a cross-sectional study. *BMC Psychiatry*, 11, 108.
- Pertl, M. M., Lawlor, B. A., Robertson, I. H., Walsh, C., & Brennan, S. (2015). Risk of Cognitive and Functional Impairment in Spouses of People With Dementia: Evidence From the Health and Retirement Study. *J Geriatr Psychiatry Neurol*, 28(4), 260-271.
- Radloff, L. C. (1977). The CES-D scale, a self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1(3), 385-401.
- Roberts, J. S. (2000). Anticipating response to predictive genetic testing for Alzheimer's disease: a survey of first-degree relatives. *Gerontologist*, 40(1), 43-52.
- Roberts, J. S., Barber, M., Brown, T. M., Cupples, L. A., Farrer, L. A., LaRusse, S. A., . . . Green, R. C. (2004). Who seeks genetic susceptibility testing for Alzheimer's disease? Findings from a multisite, randomized clinical trial. *Genet Med*, 6(4), 197-203.
- Roberts, J. S., & Connell, C. M. (2000). Illness representations among first-degree relatives of people with Alzheimer disease. *Alzheimer Dis Assoc Disord*, 14(3), 129-136, Discussion 127-128.
- Roberts, J. S., Karlawish, J. H., Uhlmann, W. R., Petersen, R. C., & Green, R. C. (2010). Mild cognitive impairment in clinical care: a survey of American Academy of Neurology members. *Neurology*, 75(5), 425-431.

- Roberts, J. S., McLaughlin, S. J., & Connell, C. M. (2014). Public beliefs and knowledge about risk and protective factors for Alzheimer's disease. *Alzheimers Dement*.
- Sperling, R., Mormino, E., & Johnson, K. (2014). The evolution of preclinical Alzheimer's disease: implications for prevention trials. *Neuron*, 84(3), 608-622.
- Steffick, D. (2000). Documentation of Affective Functioning Measures in the Health and Retirement Study. Retrieved from <http://hrsonline.isr.umich.edu/sitedocs/userg/dr-005.pdf>
- Suhr, J. A., & Kinkela, J. H. (2007). Perceived threat of Alzheimer disease (AD): the role of personal experience with AD. *Alzheimer Dis Assoc Disord*, 21(3), 225-231.
- Sun, F., Gao, X., & Coon, D. W. (2015). Perceived threat of Alzheimer's disease among chinese american older adults: the role of Alzheimer's disease literacy. *J Gerontol B Psychol Sci Soc Sci*, 70(2), 247-257.
- Turvey, C. L., Wallace, R. B., & Herzog, R. (1999). A revised CES-D measure of depressive symptoms and a DSM-based measure of major depressive episodes in the elderly. *Int Psychogeriatr*, 11(2), 139-148.
- U.S. Department of Health and Human Services, & Office of Disease Prevention and Health Promotion. Healthy People 2020. Retrieved from <https://www.healthypeople.gov/2020/topics-objectives/topic/dementias-including-alzheimers-disease/objectives>
- University of Michigan. (2010). *2010 HRS Core Fat Files (Final) RAND (v.C)*.
- Warwick, H. M. C., & Salkovskis, P. M. (1990). Hypochondriasis. *Behav Res Ther*, 28, 105-117.
- Werner, P. (2003). Knowledge about symptoms of Alzheimer's disease: Correlates and relationships to help-seeking behavior. *International Journal of Geriatric Psychiatry*, 18, 1029-1036.
- Williams, P. G. (2006). The psychopathology of self-assessed health: A cognitive approach to health anxiety and hypochondriasis. *Cogn Ther Res*, 28, 629-644.



## **CHAPTER 4**

### **Demographic, Health Care Access, and Health Status Predictors of Help-Seeking Behavior for Subjective Memory Complaints among Older Adults**

#### **Introduction**

As the population ages, the number of Americans with Alzheimer's disease (AD) is projected to grow rapidly with significant social, economic, and health-related consequences (Hebert, Weuve, Scherr, & Evans, 2013). The rising prevalence of AD, and the prospect of new early stage interventions in the years to come, have led to an increased national focus on ensuring timely and accurate diagnosis (Alzheimer's Association and Centers for Disease Control and Prevention, 2013; U.S. Department of Health and Human Services, 2016) for which there may be personal and social benefits.

A diagnosis that is made when patients first begin to notice cognitive changes may allow more time for patients and families to make plans and health care decisions, and to access treatment, care and support (de Vugt & Verhey, 2013; Relkin, 2000; World Health Organization, 2012). Pharmaceutical therapies, when started in the early stages of the disease, can be effective at reducing symptom severity and enhance quality of life (National Institute on Aging, 2014). Timely diagnosis may alleviate stress, anxiety and uncertainty among patients and families (de Vugt & Verhey, 2013). Societal costs associated with the disease may be reduced with timely diagnosis. Earlier diagnosis of dementia may lessen the chances of hospitalizations due to disease-related catastrophic events (e.g., motor vehicle accidents and major financial losses), and early initiation of treatment may prolong time to nursing home placement, disability, and other

costly outcomes (Relkin, 2000; Weimer & Sager, 2009). A recent study found that older adults with probable dementia who have not received a diagnosis were more likely to report engaging in potentially unsafe behaviors (i.e., driving, preparing hot meals, managing finances and medications, attending medical visits alone) compared to those with a diagnosis (Amjad, Roth, Samus, Yasar, & Wolff, 2016). In addition, prompt evaluation of AD can also help to identify or rule out other modifiable conditions that can cause cognitive changes, such as medication side effects, sleep problems, and depression and anxiety.

While the overall benefits of early diagnosis may be significant, it is important to note that there are also concerns about potential harms. Receiving a dementia diagnosis can be a highly stressful and emotional event for some patients and families (Aminzadeh, Byszewski, Molnar, & Eisner, 2007; Connell, Boise, Stuckey, Holmes, & Hudson, 2004; Holroyd, Turnbull, & Wolf, 2002), and some physicians perceive little value in early diagnosis or express reluctance to disclose out of concerns about causing unnecessary distress (Boise, Camicioli, Morgan, Rose, & Congleton, 1999; Millard & Baune, 2009; Milne, Woolford, Mason, & Hatzidimitriadou, 2000). Currently, the U.S. Preventive Services Task Force has concluded there is insufficient evidence to assess the balance of benefits and harms regarding universal screening of older adults for cognitive impairment (Moyer & U. S. Preventive Services Task Force, 2014).

Evidence shows that more than half of older adults with AD or other dementias in the U.S. do not receive a formal diagnosis (Amjad et al., 2016; Kotagal et al., 2015). A nationally representative study of persons age 70 or older found that over half (55.2%) of 297 participants who met criteria for dementia had not received a cognitive evaluation by a doctor, and estimated that around 1.8 million elderly Americans with dementia have not been evaluated for cognitive concerns (Kotagal et al., 2015). Similarly, in a study of Medicare beneficiaries aged 65 or older

enrolled in the National Health and Aging Trends Study, Amjad et al. (2016) found that of 1,038 participants classified as having probable dementia, 581 (56%) had not been formally diagnosed. When a diagnosis is received, the disease may have progressed to a more advanced stage where some of the potential personal, treatment, and social benefits may no longer be fully realized. In addition, racial and ethnic disparities in dementia diagnoses exist. A growing body of evidence suggests that older African American and Hispanics are disproportionately affected by AD and that missed and delayed diagnoses are more prevalent among these groups (Alzheimer's Association, 2010, 2014; Clark et al., 2005; Fitten, Ortiz, & Ponton, 2001). Studies show that African Americans and Hispanics are often diagnosed at later stages of the disease, with long delays between presentation of symptoms and diagnosis (Clark et al., 2005; Fitten et al., 2001).

Many potential barriers to early or timely dementia diagnosis have been identified. These include health care system and provider barriers, such as health care access challenges, physician attitudes about dementia and early diagnosis, and limited training, knowledge, resources and time to make a diagnosis (Bradford, Kunik, Schulz, Williams, & Singh, 2009; Hinton et al., 2007; Pentzek et al., 2009; Turner et al., 2004); as well as patient and caregiver barriers, such as non-recognition of symptoms by affected individuals and their families (Knopman, Donohue, & Guterman, 2000; Lehmann, Black, Shore, Kasper, & Rabins, 2010). However, there are many older adults who recognize they are experiencing cognitive changes and who are concerned about these changes, but do not actively seek help or consult their physicians (Hurt, Burns, Brown, & Barrowclough, 2012; Jorm et al., 2004; Waldorff, Rishoj, & Waldemar, 2008). For instance, in a study of elderly patients at 17 general practices, only 33 (18.6%) of 177 with memory complaints had consulted their physician (Waldorff et al., 2008). Yet we know very

little about who these people are and what factors might influence their decisions to discuss their concerns with a doctor.

A small but growing body of literature on help-seeking for dementia symptoms suggests there may be a number of reasons why patients experiencing memory complaints do not seek help. Broadly, these factors include demographic characteristics, knowledge, beliefs and personal experiences, psychosocial factors (e.g., social support, perceived threat of disease), cognitive and disease-related factors (e.g., disease severity and functional impairment), as well as health care policies, access, and services (see Chapter 2 for summary of results from a systematic literature review). Much of this research, however, is based on small convenience samples of older adults with limited racial and ethnic diversity. Few studies have also examined predictors of help-seeking behavior using population-based or nationally representative samples.

One exception is a study by Kotagal et al. (2015), which used U.S. nationally representative data from the Health and Retirement Study to explore the influence of a variety of sociodemographic factors—including age, sex, race, education, socio-economic status, marital status, number of children, functional disability, and severity of dementia—on the likelihood of receiving a cognitive evaluation by a doctor. Only marital status and severity of dementia symptoms were found to be significant factors, with those who were currently married (compared to currently unmarried) and those with more severe dementia (as indicated by performance on the Dementia Severity Rating Scale, Clinical Dementia Rating, and Mini-Mental State Examination) being more likely to receive a cognitive evaluation. While the study by Kotagal et al. (2015) provides insight into factors related to receiving a cognitive evaluation, the study data are from 2002, well before the start of the Medicare Annual Wellness Visit. In

addition, the study did not examine health care access factors (e.g., health care coverage, cost, services), that may serve as barriers to help-seeking.

In the present study, we use population-based data from the 2011 Behavioral Risk Factor Surveillance System (BRFSS) to examine help-seeking behavior among older adults with subjective memory complaints. The aim is to inform the development of decision making models concerning AD diagnosis and treatment through an exploration of demographic, health care access, and health status predictors of help-seeking behavior. Specifically, we ask the following question: what is the association among demographic factors (i.e., age, gender, race, education, marital status, geographic region), health care access (i.e., health care coverage, cost and services), health status (i.e., functional difficulty, mental and physical health), and help-seeking behavior for memory complaints? Based on prior research, we hypothesize that respondents who are older (Werner, 2003b), male (Hodgson & Cutler, 2004), Hispanic or non-Hispanic Black (Alzheimer's Association, 2014; Clark et al., 2005; Fitten et al., 2001), unmarried (Kotagal et al., 2015), who have lower levels of education (Hodgson & Cutler, 2004), and/or greater functional difficulty (Ramakers et al., 2009) would be significantly less likely to talk with a health care professional about memory concerns. We also hypothesize that respondents with poorer mental health and physical health, who have health insurance coverage, and/or a primary care provider would be more likely to seek help from a health care professional, while respondents who reported that cost was a barrier to receiving care in the last 12 months would be less likely to seek help.

## **Methods**

### ***Participants and procedures***

Public release data from the 2011 Behavioral Risk Factor Surveillance System (BRFSS) survey were used for this analysis. The BRFSS is a U.S. national telephone survey system that monitors state-level prevalence of health-related risk behaviors among adults. Established in 1984 by the Centers for Disease Control and Prevention (CDC), the BRFSS is currently the largest continuously conducted telephone survey in the world (Centers for Disease Control and Prevention, 2013a). The BRFSS collects data throughout the year from all 50 states, the District of Columbia, and three U.S. territories. With technical assistance from the CDC, state health departments administer the survey through in-house interviewers, telephone call centers, and universities. The survey includes a standardized core questionnaire, optional modules, and state-added questions (Centers for Disease Control and Prevention, 2013b).

In 2011, 21 of the 50 states that conducted the BRFSS survey included a 10-question cognitive impairment module in their surveys (see Appendix for module survey questions and a list of participating states). Given that only 7 of 21 states conducted cell phone interviews in addition to landline (constituting 2.8% of eligible respondents), and landline and cell phone respondents have been found to differ (Hu, Balluz, Battaglia, & Frankel, 2011), we restricted this analysis to landline telephone interviews with a median landline response rate of 53.4% across the 21 states (Centers for Disease Control and Prevention, 2013c). We also restricted the analysis to respondents aged  $\geq 60$  from the 21 states ( $n = 59,852$ ), as AD risk substantially increases in older age. In addition, only respondents who answered “yes” to the question “During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?” were included in the analysis ( $n = 6,807$ ). The 6,807 respondents reporting confusion or memory loss were previously compared to those aged  $\geq 60$  in the larger BRFSS sample on a number of key demographic characteristics. Several significant differences were

reported, with the percentage reporting confusion or memory loss being significantly higher among persons aged  $\geq 85$  years, Hispanics or Latinos (compared with Whites), persons with less than a high school education, persons who reported they were disabled, and persons who were unable to work (Centers for Disease Control and Prevention, 2013c).

## *Measures*

### *Demographics*

Demographic characteristics were assessed using BRFSS core survey questions—age (recoded into 3 categories: 60-64 years, 65-74 years,  $\geq 75$  years), gender (male or female), race/ethnicity (recoded into 4 categories: Hispanic, non-Hispanic Black, non-Hispanic White, other non-Hispanic race or non-Hispanic multiracial), education (recoded into 3 categories: no degree, GED or high school diploma, some college or college graduate), marital status (married or single), and geographic region (recoded from zip codes: Northeast, Midwest, South, West). Age was categorized to assess help-seeking in adults aged 60-64 years with memory concerns who are in the period prior to the emergence of late onset AD, adults aged 65-74 with memory concerns who are at the stage when the risk of late onset AD begins to increase, and adults aged  $\geq 75$  years who are at the stage when the vast majority of late onset AD cases occur (Alzheimer's Association, 2016)

### *Help-seeking*

One item from the cognitive impairment module was used to examine help-seeking behavior: “Has anyone discussed with a health care professional, increases in your confusion or memory loss? (Yes/No).

### *Functional difficulty*

Functional decline related to memory loss was assessed through two items from the cognitive impairment module: 1) “During the past 12 months, how often have you given up household activities or chores you used to do, because of confusion or memory loss that is happening more often or is getting worse?,” and 2) “During the past 12 months, how often has confusion or memory loss interfered with your ability to work, volunteer, or engage in social activities?” (Response options: 1 = always, 2 = usually, 3 = sometimes, 4 = rarely, 5 = never). A composite score was created by reverse coding scores to increase interpretability and summing scores across the two items (possible range: 2-10, low to high functional difficulty). The composite measure had a Cronbach’s alpha of 0.72.

#### *Mental health status*

Mental health status was assessed with one item in the BRFSS core survey: “Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good? (Response options: indicate number of days out of 30, none, don’t know/not sure, refused). This item is included in the BRFSS survey as part of the health-related quality of life (HRQOL) index (Hagerty et al., 2011).

#### *Physical health status*

Physical health status was ascertained through one item in the BRFSS core survey: “Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good? (Response options: indicate number of days out of 30, none, don’t know/not sure, refused). This item is included in the BRFSS survey as part of the health-related quality of life (HRQOL) index (Hagerty et al., 2011).



### *Health insurance coverage*

One item from the BRFSS core survey was used to assess health insurance coverage by asking respondents whether they have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or governmental plans such as Medicare or Indian Health Services (response options: yes, no, don't know/not sure, refused).

### *Access to primary care provider*

Access to a primary care provider was assessed through one item in the core BRFSS survey: "Do you have one person you think of as your personal doctor or health care provider?" (Response options: yes, only one; more than one; no; don't know/not sure, refused). Responses were recoded as either yes (yes, only one, and more than one) or no.

### *Cost as a barrier to care*

One item from the core BRFSS survey was used to examine cost as a barrier to care: "Was there a time in the past 12 months when you needed to see a doctor but could not because of cost?" (Response options: yes, no, don't know/not sure, refused).

### *Analysis*

All analyses were conducted using SAS software, version 9.4 of the SAS System for Windows (SAS Institute, 2013). The 2011 BRFSS survey used a weighting methodology called iterative proportional fitting, or "raking," which adjusts the data to create a more representative sample while reducing non-response bias and error within estimates (Centers for Disease Control and Prevention, 2015). Complex survey sampling design features, including clustering, stratification, and weights, were taken into account in this analysis. Because the analysis was

restricted to landline telephone interviews, a final weight variable for the landline only data set (\_LANDWT) was used.

A complete case analysis using logistic regression of the binary dependent variable help-seeking behavior, revealed that 826 (12.1%) of 6,807 respondents had missing data on one or more variables. When data were missing, respondents either declined to answer a question, answered “don’t know/not sure,” or were missing an answer. An examination of missing data revealed an arbitrary missing data pattern with varying amounts of missing data on the variables education, functional difficulty, mental health status, physical health status, insurance coverage, access to primary care provider, cost as a barrier to care, and help-seeking behavior. We chose to use the FCS method for multiply imputing missing data, which is a flexible method for imputing a mixture of variable types with an arbitrary missing data pattern (Berglund & Heeringa, 2014). PROC MI code included  $M=5$  repetitions and 40 burn-in iterations. The imputation model included all of the variables of interest in this study, including the dependent variable and interactions as well as complex sample design characteristics. The dependent variable was included to prevent bias in the multiple imputation estimation and inference (Berglund & Heeringa, 2014). PROC MIANALYZE was used to combine the MI repetition analysis results to get parameter estimates and standard errors. Missing data on eight measures were imputed, including: 13 missing data points (0.2% of responses) on education level, 191 missing data points (2.8% of responses) on help-seeking behavior, 287 missing data points (4.2% of responses) on functional difficulty, 251 missing data points (3.7% of responses) on mental health status, 300 missing data points (4.4%) on physical health status, 16 missing data points (0.2% of responses) on health insurance coverage, 18 missing data points (2.6% of responses) on access to primary care provider, and 25 missing data points (3.7% of responses) on cost as a barrier to

care. A comparison of the results of the full multiply imputed analysis to that of the single imputation results, revealed very little difference between the results (Table 4-1). Based on the small differences, and the low percentage of missing values, we chose to proceed with using a single imputation repetition for the analyses in this paper.

Univariate descriptive analyses were performed to explore the sample in terms of demographic characteristics, health care access, health status, and help-seeking behavior. Bivariate associations were explored through chi-square and correlation analyses. Chi-square tests of association were performed to examine inter-relationships between categorical predictors, while a Pearson's *r* correlation matrix was generated to explore inter-relationships between continuous and ordinal predictors. Multicollinearity was assessed by examining bivariate correlations in a Pearson's *r* correlation matrix.

A multivariable logistic regression analysis was performed to examine demographic, health care access, and health status predictors of help-seeking behavior among participants with self-reported memory complaints. Figure 4-1 shows the conceptual model that was tested for this study. Because functional difficulty may account for a disproportionately large amount of variance in the model, a hierarchical approach to analyzing the data was taken to address this issue. Demographic variables were entered first (model 1), followed by health care access variables (model 2), and then health status variables which include functional difficulty (model 3). The full model contained 12 predictors: age (60-64, 65-74,  $\geq 75$ ), gender (male or female), race/ethnicity (Hispanic, non-Hispanic Black, non-Hispanic White, and other non-Hispanic race or non-Hispanic multiracial), education (No degree, GED or high school diploma, some college or college graduate), marital status (married or single), geographic region (Northeast, Midwest, South, West), health insurance coverage, access to primary care provider, cost as a barrier to

care, mental health status, physical health status, and functional difficulty. Age was entered into the model as a categorical variable for ease of interpretation and to assess differences in help-seeking between age groups, as dementia risk substantially increases after age 65. We were interested in comparing help-seeking in adults aged 60-64 years with memory concerns who are in the period prior to the emergence of late onset AD, adults aged 65-74 with memory concerns who are at the stage when the risk of late onset AD begins to increase, and adults aged  $\geq 75$  years who are at the stage when the vast majority of late onset AD cases occur (Alzheimer's Association, 2016). Because of the typically strong association between age and cognitive decline, and the potential for residual confounding within each age group, we also ran the full logistic regression analysis with age entered as a continuous variable to examine whether the results differed from our original model with age as a categorical variable. We did not find any notable differences between the results of these two models. First order interactions were also examined.

## **Results**

### **Respondent Characteristics**

Table 4-2 summarizes the unweighted respondent counts and population weighted percentages of demographic characteristics for the BRFSS population. The mean age was 71.6 years (SE = 0.21, range: 60-99). Weighted population estimates showed a fairly even distribution across the three age groups, although there was a slightly lower percentage in the 60-64 age group. Nearly three quarters identified as non-Hispanic White (73.8%), while a quarter of the population identified as either Hispanic (9.6%), Non-Hispanic Black (8.6%), or identified as another non-Hispanic race or non-Hispanic multiracial (8.0%). Just under half (46.0%) reported attending college or having a college degree.

Table 4-3 presents the weighted means and standard errors, and the score ranges for the health status and health care access variables. Weighted estimates showed low levels of functional difficulty due to confusion or memory loss (Mean = 3.69, Range = 2-10, SE = 0.06); 43.6% of the population reported no functional difficulty over the past 12 months. There was a mean number of 7.65 days (range: 0-30 days) of poor mental health, and 10.81 days (range: 0-30 days) of poor physical health. Most people reported having some form of health insurance coverage (94.0%) and having access to a primary care provider (95.9%). Only 14.1% reported that cost had been a barrier to receiving care in the past 12 months. A vast majority of people reported that increased confusion or memory loss had not been discussed with a health care professional (80.0%).

### **Bivariate Summaries**

Tables 4-4 and 4-5 present bivariate summaries of demographic, health care access, and health status predictors. Chi-square tests of association showed a number of significant relationships between demographic predictors, and health care access predictors (Table 4-4). Help-seeking behavior was significantly associated with two variables: age group ( $\chi^2$  (2, 12538) = 56.25,  $p$  = 0.001), and having access to a primary care provider ( $\chi^2$  (1, 6269) = 31.01  $p$  < 0.0001). Post hoc pair-wise comparisons revealed significant differences in help-seeking between 60-64 and 65-74 age groups ( $\chi^2$  (1, 3510) = 19.43,  $p$  = 0.034), and 60-64 and  $\geq 75$  age groups ( $\chi^2$  (1, 3803) = 53.62,  $p$  = 0.0002). A higher weighted percentage of people aged 60-64 years had sought help (7.3%) compared to 65-74 years (6.8%) and  $\geq 75$  years (5.9%). Just under 20% of people who had a primary care provider had sought help compared to 0.28% without a primary care provider.

Pearson r correlations showed significant positive associations between health status variables, including: functional difficulty and mental health, functional difficulty and physical health, and mental health and physical health. Help-seeking behavior showed significant inverse associations with functional difficulty, mental health, and physical health. We did not find evidence of the independent variables being highly correlated, with Pearson correlations ranging from -0.268 (gender and marital status) to 0.355 (no. days mental health not good and no. days physical health not good).

### **Regression Analysis of Help-Seeking Behavior**

Table 4-6 shows the results of the logistic regression analysis for help-seeking behavior. Five predictors emerged as significantly associated with help-seeking behavior in the full model (model 3). Relative to those who identified as non-Hispanic White, those who identified as another non-Hispanic race or non-Hispanic multiracial had about half the odds (OR = 0.52) of help-seeking for memory complaints. Compared to those with some college or a college degree, those with no degree (OR = 0.58) or with a high school diploma (OR = 0.56) also had less than half the odds of help-seeking. Respondents who had access to a primary care provider had nearly 3 times the odds of help-seeking. Those who reported having more days of poor mental health had significantly greater odds of seeking help (OR = 1.02), as did respondents who reported higher levels of functional difficulty (OR = 1.36).

There were several notable differences across the regression models. Models 1 and 2 showed a significant association between age group and help-seeking behavior, whereas model 3 did not. Compared to those aged  $\geq 75$  years, those in the 60-64 age group had significantly higher odds of help-seeking (model 1: OR = 1.68; model 2: OR = 1.74). In model 3, “Other race” and “No degree” categories also emerged as significant, whereas these effects did not appear in

models 1 and 2.

Only one significant interaction effect was found between age group and having access to a primary care provider in explaining help-seeking behavior. Relative to those aged  $\geq 75$  years without a primary care provider, respondents in the 60-64 age group who had a primary care provider were approximately 14 times more likely to seek help (OR = 14.67, SE = 0.72,  $p = 0.0002$ ), and respondents in the 65-74 age group were nearly 4 times more likely to seek help (OR = 3.97, SE = 0.68,  $p = 0.0411$ ).

### **Discussion**

The present study examined demographic, health care access, and health status predictors of discussing memory concerns with a doctor. In the full model, five factors emerged as significantly associated with help-seeking: race/ethnicity, education level, access to primary care provider, mental health status, and functional difficulty. These findings point to the important roles that education and having access to a primary care provider may play in whether someone seeks help for memory complaints. The findings also suggest that help-seeking occurs when significant memory problems interfere with independent function and daily activities, and when quality of life as it relates to mental health begins to be affected.

Several studies have found evidence that patients may be more likely to acknowledge the presence of a health condition and discuss concerns with their doctor when the disease becomes severe enough to interfere with daily functioning (Leung et al., 2011; McCleary et al., 2013; Morhardt, Pereyra, & Iris, 2010; Mukadam, Cooper, Basit, & Livingston, 2011; Pires et al., 2012; Ramakers et al., 2009). As noted previously, Kotagal et al. (2015), using U.S. nationally representative data, observed that respondents with more severe dementia had an increased odds of receiving a cognitive assessment. To our knowledge, only one other study using 2011 BRFSS

data has reported an association between functional difficulty and talking to a health care provider about increased confusion or memory loss (Centers for Disease Control and Prevention, 2013c). However, our study goes beyond prior research to demonstrate that functional difficulty continues to be a strong predictor of help-seeking behavior after adjusting for a variety of other demographic and health-related factors.

Mental health was a significant predictor of help-seeking behavior in our regression model. Respondents who reported more frequent days of poor mental health were more likely to have sought help for memory concerns. Few research studies have addressed the role that mental health may play in help-seeking for memory concerns. One study has suggested that the presence of underlying depression and anxiety may impede the help-seeking process (Garcia et al., 2014), while other studies have found no significant differences in levels of anxiety and depression among help-seekers and non-help-seekers (Hurt et al., 2012; Ramakers et al., 2009). In the present study, mental health status may more accurately reflect respondents' quality of life, potentially as a consequence of increased functional difficulty and disease severity. Thus, as disease symptoms progress and quality of life as it relates to mental health deteriorates, individuals may be more likely to seek help. Mental health status may also be closely tied to health anxiety and perceived disease threat. In this case, worry about increased confusion or memory loss may be driving the association between mental health status and help-seeking behavior. Interestingly, physical health did not emerge as a significant predictor of help-seeking behavior, suggesting that the decision to discuss memory complaints with a doctor is most closely related to mental health and daily functioning. One possible explanation for this finding is that older adults with both physical and mental ailments may prioritize treating their physical



health conditions because cognitive decline is viewed by many as a natural consequence of aging.

As expected, respondents who had a primary care provider were significantly more likely to have discussed memory concerns with a health care professional. Primary care providers typically play an integral role in providing education about dementia signs and symptoms, referring patients for cognitive assessment, and in facilitating diagnosis, treatment and care. They are often viewed by patients as the first point of formal contact for discussing cognitive or memory changes (Leung et al., 2011; Low, Anstey, Lackersteen, & Camit, 2011; McCleary et al., 2013; Ploeg et al., 2009; Samsi et al., 2014; Werner, 2003b). When patients establish a relationship with a primary care provider during routine annual visits, the provider gets to know the patient's health history and personality, and may thus be more likely to notice cognitive changes over time. Similarly, patients may be more likely to discuss their health concerns with a doctor that they know and trust. On the other hand, primary care physicians can contribute to a delay in help-seeking when they do not take patient concerns seriously, excuse memory problems as part of normal aging, or choose not to refer their patient to a specialist (Boise, Morgan, Kaye, & Camicioli, 1999; Connell et al., 2004; Morgan et al., 2014).

In the full model, education level and race/ethnicity were the only two demographic factors associated with help-seeking behavior. In general, people with higher levels of education tend to have higher health literacy, engage in healthier behaviors, and are more likely to seek assistance for health-related problems and participate in certain preventive and screening behaviors (Bennett, Chen, Soroui, & White, 2009; Friis, Lasgaard, Rowlands, Osborne, & Maindal, 2016). There is also evidence that education may play a role in the process of seeking out health-related information among individuals with concerns about AD. In a study of 40- to

60-year-old adults with concerns about developing AD, respondents with higher levels of education were found to have utilized more organizational and informational sources to allay or confirm their fears about AD (Hodgson & Cutler, 2004). In the present study, respondents with no degree or a high school diploma had a significantly lower likelihood of seeking help compared to respondents who were college educated. This may suggest that education level is a factor in knowing when and how to seek out health-related information resources, or it may also relate to the availability of and access to community resources that may aid or impede the help-seeking process.

Compared to those who identified as non-Hispanic White, respondents in the “other race or multiracial” category had a significantly lower likelihood of seeking help for memory complaints. While the full model showed that Hispanic and non-Hispanic Black respondents had slightly lower odds of seeking help compared to non-Hispanic Whites, these differences by race/ethnicity did not reach significance. This is contrary to evidence from the research literature on racial/ethnic disparities in diagnoses of dementia, which shows long delays between presentation of symptoms and diagnosis among older African Americans and Hispanics (Alzheimer's Association, 2010, 2014; Clark et al., 2005; Fitten et al., 2001). This may suggest that disparities in diagnoses of dementia among older African Americans and Hispanics observed in other studies may be due to factors other than the action of seeking help. Help-seeking behavior by itself, as measured in this study, does not always lead to a diagnosis from a health care professional.

While nonsignificant in the full model, age was a strong predictor of help-seeking behavior in the first model with only demographic factors, and in the second model which accounted for demographic and health care access factors. In these first two models, respondents in the 60-64

age group had a significantly greater likelihood of talking to a health care professional than respondents in the oldest age group. We know from prior research that younger individuals may have greater perceived benefits of seeking help for memory concerns (Werner, 2003a), and that older age has been associated with lower knowledge about AD (Werner, 2003b). However, the age effect disappeared with the addition of health status predictors.

We also found a significant interaction effect between age group and having access to a primary care provider, with respondents in the younger age groups (60-64 and 65-74) having a much greater likelihood of seeking help if they also had a primary care provider. Because the usual age of eligibility for Medicare benefits in the U.S. is 65, it is likely that the interaction effect may be due to respondents in the 60-64 age group not yet being eligible for Medicare coverage. In January 2011, the Medicare Annual Wellness Visit, under the Affordable Health Care Act, began providing a free cognitive evaluation. Given the overlap with 2011 BRFSS data collection, it is possible that some respondents in our sample with Medicare coverage contacted their primary care provider and took advantage of this free assessment. However, we can't confirm this speculation from our data. It is important to note that only 4.1% of respondents indicated they did not have a primary care provider, which may limit the statistical meaningfulness of these comparisons. The vast majority reported having a primary care provider, having health insurance coverage, and did not report that cost was a barrier to seeing a doctor, suggesting that these specific health care access factors were not major concerns for our older adult respondents. Future research should examine help-seeking behavior as it relates to other health care access barriers that may be especially relevant for older adult populations, such as availability of transportation to medical appointments.

There are several limitations to the present study. First, the cognitive module data come from 21 states, and may not fully represent adults with memory concerns in the U.S. as a whole. For instance, as shown in Table 4-2, there is an underrepresentation of adults from Northeastern states (10%), which only include New Hampshire, Maryland, and New York, and a notable overrepresentation of adults from Southern states, comprising 52% of respondents. Second, the cross-sectional nature of the study does not allow us to investigate causality; all findings are correlational. Third, this study used self-reported measures that were not validated through clinical assessment, and thus may be subject to recall bias. Fourth, we chose to conduct our analysis using a single imputation replicate given the small amount of missing data and the similarity between multiply imputed datasets, however, this approach may not reflect the full imputation variance. Fifth, several of the single-item measures used in this analysis do not provide much specificity or context for interpretation. For instance, the measure of mental health does not specify what problems respondents had encountered in the last month. It would be informative to know whether respondents were experiencing depression, anxiety, or other issues, and whether this was related to their memory problems or concerns. In addition, the measure for help-seeking behavior used in this study does not take into account situational factors linked with the behavior, such as who discussed the concerns with the doctor, when the concerns were discussed, and whether the person was further evaluated or diagnosed as an outcome of the conversation. Follow up questions concerning who talked with the doctor and whether the visit led to a diagnosis would have provided greater context for analysis and interpretation. Lastly, perceived threat of Alzheimer's disease was a construct missing from the BRFSS that would have made an important contribution to this study. As this measure was not included, we were

unable to examine the relationship between perceived threat of Alzheimer's disease and help-seeking for memory concerns.

Despite these limitations, this research goes beyond prior studies by investigating health status and health care access predictors of help-seeking behavior. This study is also one of only a few U.S. population-based studies to examine predictors of help-seeking behavior among a uniquely large and diverse sample of nearly 7,000 older adults who self-identified as having memory loss. Our findings also capture a snapshot of factors that may influence help-seeking for memory concerns at the time that free cognitive evaluations became available as part of the Medicare Annual Wellness Visit. As the U.S. strives to make cognitive assessment more routine and accessible in health care settings, this study provides information on what barriers may still exist to raising memory concerns with a health professional. A vast majority of respondents in our study had not sought help for memory concerns, with only 20% reporting that they or someone else had talked to a health care professional. Our findings revealed a number of factors related to talking with a health care professional about memory concerns, including demographic predictors such as education and race/ethnicity, as well as health status and access predictors such as functional difficulty, mental health, and having access to a primary care provider. These findings highlight the importance of and need for disease education and community outreach efforts to raise awareness about early dementia symptoms, and inform people about how and when to seek help and support. The findings also provide specific factors that health care providers and policy makers should consider in efforts to increase early and accurate diagnosis. For instance, there is a need to make sure that all community-dwelling older adults have access to a primary care provider who can facilitate discussions about health concerns, and monitor changes in cognition, function, and mental health. There is also a need for increased training of

primary care providers to recognize early symptoms and make referrals to specialty care (Lathren, Sloane, Hoyle, Zimmerman, & Kaufer, 2013).

While there is some debate concerning the benefits and effectiveness of early dementia diagnosis and intervention, what is clear is that there should be no barriers to receiving appropriate care and health information. Everyone should have the opportunity to express their health concerns to a primary care provider and receive timely assessment and diagnosis. To this end, our findings provide valuable insight about the help-seeking process, and provide a starting point for the development of decision-making models and interventions aimed at addressing barriers to AD diagnosis and treatment.

**Table 4-1:** Comparison of Results from Multiple Imputation and Single Imputation Models

Variables	Multiple Imputation† (Model 3) N = 6,807	Single Imputation† (Model 3) N = 6,807
	B (SE)	B (SE)
<b>Age</b>		
60-64	0.25 (0.17)	0.26 (0.16)
65-74	0.12 (0.14)	0.16 (0.14)
75 and over (ref)	0.00	0.00
<b>Female</b>	-0.10 (0.13)	-0.13 (0.13)
<b>Race/Ethnicity</b>		
Any race, Hispanic	-0.21 (0.32)	-0.23 (0.31)
Non-Hispanic Black	-0.28 (0.24)	-0.30 (0.23)
Other non-Hispanic race or non-Hispanic multiracial	<b>-0.63** (0.23)</b>	<b>-0.65** (0.23)</b>
Non-Hispanic White (ref)	0.00	0.00
<b>Education</b>		
No degree	<b>-0.57** (0.20)</b>	<b>-0.54** (0.20)</b>
GED or high school diploma	<b>-0.59*** (0.14)</b>	<b>-0.59*** (0.14)</b>
Some college or college degree (ref)	0.00	0.00
<b>Married</b>	0.22 (0.14)	0.22 (0.13)
<b>Geographic Region</b>		
Midwest	-0.005 (0.27)	-0.03 (0.27)
South	0.04 (0.23)	0.05 (0.23)
West	-0.16 (0.25)	-0.18 (0.25)
Northeast (ref)	0.00	0.00
<b>Health Insurance</b>	0.17 (0.35)	0.14 (0.35)
<b>Access to Primary Care Provider</b>	<b>1.07** (0.33)</b>	<b>1.08** (0.33)</b>
<b>Cost is a barrier</b>	-0.31 (0.22)	-0.34 (0.22)
<b>No. Days Mental Health Not Good</b>	<b>0.03*** (0.007)</b>	<b>0.02*** (0.006)</b>
<b>No. Days Physical Health Not Good</b>	0.008 (0.005)	0.008 (0.005)
<b>Functional Difficulty</b>	<b>0.30*** (0.04)</b>	<b>0.31*** (0.03)</b>
<b>Constant</b>	<b>-3.88 (0.49)</b>	<b>-3.86 (0.48)</b>

Data are weighted.

\*\*\*p<0.001; \*\*p < 0.01; \*p < 0.05.

Dependent variable: Help-seeking behavior (1 = sought help, 2 = did not seek help);

Reference category = did not seek help.

†Includes imputed missing values for the following variables: education, health insurance, access to primary care provider, cost as a barrier, no. days mental health not good, no. days physical health not good, functional difficulty, and help-seeking behavior

**Table 4-2:** Unweighted Respondent Counts and Population Weighted Percentages of Demographic Characteristics for the BRFSS Population (N = 6,807)

<b>characteristics</b>	<b>n</b>	<b>weighted % (SE) / mean (SE)</b>
<b>Age</b>		<b>71.6 (0.21), range: 60-99</b>
60-64	1,507	28.6 (1.2)
65-74	2,505	35.0 (1.1)
75 and over	2,795	36.4 (1.1)
<b>Female</b>	4,130	52.6 (1.2)
<b>Race and ethnicity</b>		
Non-Hispanic White	5,475	73.8 (1.1)
Other non-Hispanic race or non-Hispanic multiracial*	571	8.0 (0.8)
Non-Hispanic Black	529	8.6 (0.7)
Hispanic	232	9.6 (1.1)
<b>Education†</b>		
No degree	1,028	24.9 (1.2)
GED or high school diploma	2,234	29.1 (1.1)
Some college or college degree	3,545	46.0 (1.2)
<b>Married</b>	3,104	47.7 (1.2)
<b>Region</b>		
South	3,252	52.0 (0.69)
West	1,526	17.7 (0.48)
Midwest	1,468	20.3 (0.54)
Northeast	561	10.0 (0.46)

Percentages and estimates are weighted.

\*Other includes Asian, Native Hawaiian or Other Pacific Islander, American Indian / Alaska Native, Other, Don't know / Not sure, Multiracial but preferred race not asked.

†Education includes 13 imputed values - weighted % and SE have been adjusted accordingly.



**Table 4-3:** Means, SE, and Score Range of Health Status and Health Care Access Variables (N = 6,807)

<b>Variables</b>	<b>Mean</b>	<b>SE</b>	<b>Score range (interpretation)</b>
Functional difficulty ( <i>composite</i> )	3.69	0.06	2-10 (low to high functional difficulty)
Number of days mental health not good	7.65	0.29	0-30 (0 - 30 days)
Number of days physical health not good	10.81	0.30	0-30 (0 - 30 days)
Health insurance	1.06	0.01	1-2 1 = yes, have insurance (94.0%) 2 = no, do not have insurance or don't know (6.0%)
Access to primary care provider	1.04	0.004	1-2 1 = yes, have provider (95.9%) 2 = no, do not have provider or don't know (4.1%)
Cost as a barrier to care	1.86	0.01	1-2 1 = yes, cost is a barrier (14.1%) 2 = no, cost is not a barrier (85.9%)
Help-seeking behavior	1.80	0.01	1-2 1 = yes, sought help (20.0%) 2 = no, did not seek help (80.0%)

Mean and SE estimates are weighted.  
Note: Includes imputed missing values.

**Table 4-4:** Bivariate Summary of Associations Among Categorical Predictors of Help-Seeking Behavior (Chi-square tests of association; N = 6,807)

	1	2	3	4	5	6	7	8	9	10
<b>1. Age (categorical)</b>	—									
<b>2. Gender</b>		—								
<b>3. Race/Ethnicity</b>	$\chi^2 = 0.78$ (2, 12538) $p = 0.916$	—								
<b>4. Education</b>	$\chi^2 = 176.06$ (6, 37614) $p < 0.0001$	$\chi^2 = 10.78$ (3, 18807) $p = 0.654$	—							
<b>5. Marital Status</b>	$\chi^2 = 19.43$ (4, 25076) $p = 0.401$	$\chi^2 = 39.48$ (2, 12538) $p = 0.016$	$\chi^2 = 517.04$ (6, 37614) $p < 0.0001$	—						
<b>6. Region</b>	$\chi^2 = 73.81$ (2, 12538) $p = 0.0002$	$\chi^2 = 468.09$ (1, 6269) $p < 0.0001$	$\chi^2 = 156.70$ (3, 18807) $p < 0.0001$	$\chi^2 = 128.24$ (2, 12538) $p < 0.0001$	—					
<b>7. Health Insurance</b>	$\chi^2 = 24.78$ (6, 37614) $p = 0.404$	$\chi^2 = 16.54$ (3, 18807) $p = 0.233$	$\chi^2 = 392.29$ (9, 56421) $p < 0.0001$	$\chi^2 = 239.18$ (6, 37614) $p < 0.0001$	$\chi^2 = 33.31$ (3, 18807) $p = 0.034$	—				
<b>8. Primary Care Provider</b>	$\chi^2 = 408.40$ (2, 12538) $p < 0.0001$	$\chi^2 = 0.0001$ (1, 6269) $p = 0.998$	$\chi^2 = 153.69$ (3, 18807) $p < 0.0001$	$\chi^2 = 30.68$ (2, 12538) $p = 0.069$	$\chi^2 = 0.013$ (1, 6269) $p = 0.964$	$\chi^2 = 32.83$ (3, 18807) $p = 0.062$	—			
	$\chi^2 = 35.63$ (2, 12538) $p = 0.001$	$\chi^2 = 3.61$ (1, 6269) $p = 0.251$	$\chi^2 = 15.85$ (3, 18807) $p = 0.211$	$\chi^2 = 28.60$ (2, 12538) $p = 0.006$	$\chi^2 = 14.34$ (1, 6269) $p = 0.034$	$\chi^2 = 4.51$ (3, 18807) $p = 0.672$	$\chi^2 = 429.95$ (1, 6269) $p < 0.0001$	—		

**9. Cost as a Barrier to Care**

$\chi^2 = 314.49$ <b>(2, 12538)</b> $p < 0.0001$	$\chi^2 = 12.54$ (1, 6269) $p = 0.175$	$\chi^2 = 147.59$ <b>(3, 18807)</b> $p < 0.0001$	$\chi^2 = 31.88$ (2, 12538) $p = 0.070$	$\chi^2 = 16.05$ (1, 6269) $p = 0.097$	$\chi^2 = 22.93$ (3, 18807) $p = 0.170$	$\chi^2 = 511.28$ <b>(1, 6269)</b> $p < 0.0001$	$\chi^2 = 102.97$ <b>(1, 6269)</b> $p < 0.0001$	—
--	--	--	---	--	---	---	---	---

**10. Help-seeking Behavior**

$\chi^2 = 56.25$ <b>(2, 12538)</b> $p = 0.001$	$\chi^2 = 16.89$ (1, 6269) $p = 0.059$	$\chi^2 = 19.10$ (3, 18807) $p = 0.442$	$\chi^2 = 19.93$ (2, 12538) $p = 0.174$	$\chi^2 = 5.48$ (1, 6269) $p = 0.289$	$\chi^2 = 25.95$ (3, 18807) $p = 0.096$	$\chi^2 = 0.009$ (1, 6269) $p = 0.977$	$\chi^2 = 31.01$ <b>(1, 6269)</b> $p < 0.0001$	$\chi^2 = 1.10$ (1, 6269) $p = 0.687$	—
--	--	---	---	---	---	--	--	---	---

Data are weighted.

Includes Rao-Scott F adjusted chi-square statistic and Satterthwaite approximation for degrees of freedom.

Note: Includes imputed missing values.

**Table 4-5:** Bivariate Summary with Pearson Correlations for Help-Seeking Behavior and Health Status Predictors (N = 6,807)

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
<b>1. Functional Difficulty</b>	—			
<b>2. No. of Days Mental Health Not Good</b>	<b>0.336**</b>	—		
<b>3. No. of Days Physical Health Not Good</b>	<b>0.276**</b>	<b>0.355**</b>	—	
<b>4. Help-seeking Behavior</b>	<b>-0.265**</b>	<b>-0.181**</b>	<b>-0.119**</b>	—

Data are unweighted.

**\*\*p < 0.001**

Note: Includes imputed missing values.

**Table 4-6: Summary of Logistic Regression Analysis of Help-seeking Behavior (N = 6,807)**

Variables	Model 1	Model 2	Model 3
	OR (95% CI)	OR (95% CI)	OR (95% CI)
<b>Age</b>			
60-64	<b>1.68*** (1.25-2.27)</b>	<b>1.74*** (1.26-2.38)</b>	1.29 (0.94-1.78)
65-74	1.24 (0.96-1.60)	1.23 (0.96-1.59)	1.18 (0.90-1.54)
75 and over (ref)	1.00	1.00	1.00
<b>Female</b>	0.81 (0.63-1.06)	0.82 (0.63-1.06)	0.88 (0.68-1.14)
<b>Race/Ethnicity</b>			
Any race, Hispanic	1.23 (0.62-2.44)	1.23 (0.63-2.41)	0.80 (0.43-1.47)
Non-Hispanic Black	0.83 (0.53-1.30)	0.85 (0.55-1.32)	0.74 (0.47-1.17)
Other non-Hispanic race or non-Hispanic multiracial	0.67 (0.40-1.12)	0.66 (0.40-1.09)	<b>0.52** (0.34-0.81)</b>
Non-Hispanic White (ref)	1.00	1.00	1.00
<b>Education</b>			
No degree	0.81 (0.56-1.17)	0.83 (0.57-1.20)	<b>0.58** (0.39-0.87)</b>
GED or high school diploma	<b>0.70* (0.53-0.93)</b>	<b>0.71* (0.54-0.93)</b>	<b>0.56*** (0.42-0.73)</b>
Some college or college degree (ref)	1.00	1.00	1.00
<b>Married</b>	1.02 (0.79-1.33)	1.02 (0.78-1.33)	1.24 (0.96-1.62)
<b>Geographic Region</b>			
Midwest	0.92 (0.55-1.53)	0.92 (0.55-1.52)	0.97 (0.58-1.63)
South	1.08 (0.70-1.68)	1.09 (0.70-1.69)	1.05 (0.67-1.64)
West	0.67 (0.42-1.07)	0.68 (0.42-1.08)	0.83 (0.51-1.35)
Northeast (ref)	1.00	1.00	1.00
<b>Health Insurance</b>		1.10 (0.51-2.37)	1.16 (0.58-2.30)
<b>Access to Primary Care Provider</b>		<b>3.67*** (1.88-7.14)</b>	<b>2.95** (1.56-5.59)</b>
<b>Cost is a barrier</b>		1.05 (0.69-1.61)	0.71 (0.47-1.09)
<b>No. Days Mental Health Not Good</b>			<b>1.02*** (1.01-1.04)</b>
<b>No. Days Physical Health Not Good</b>			1.01 (0.99-1.02)
<b>Functional Difficulty</b>			<b>1.36*** (1.27-1.45)</b>

Data are weighted.

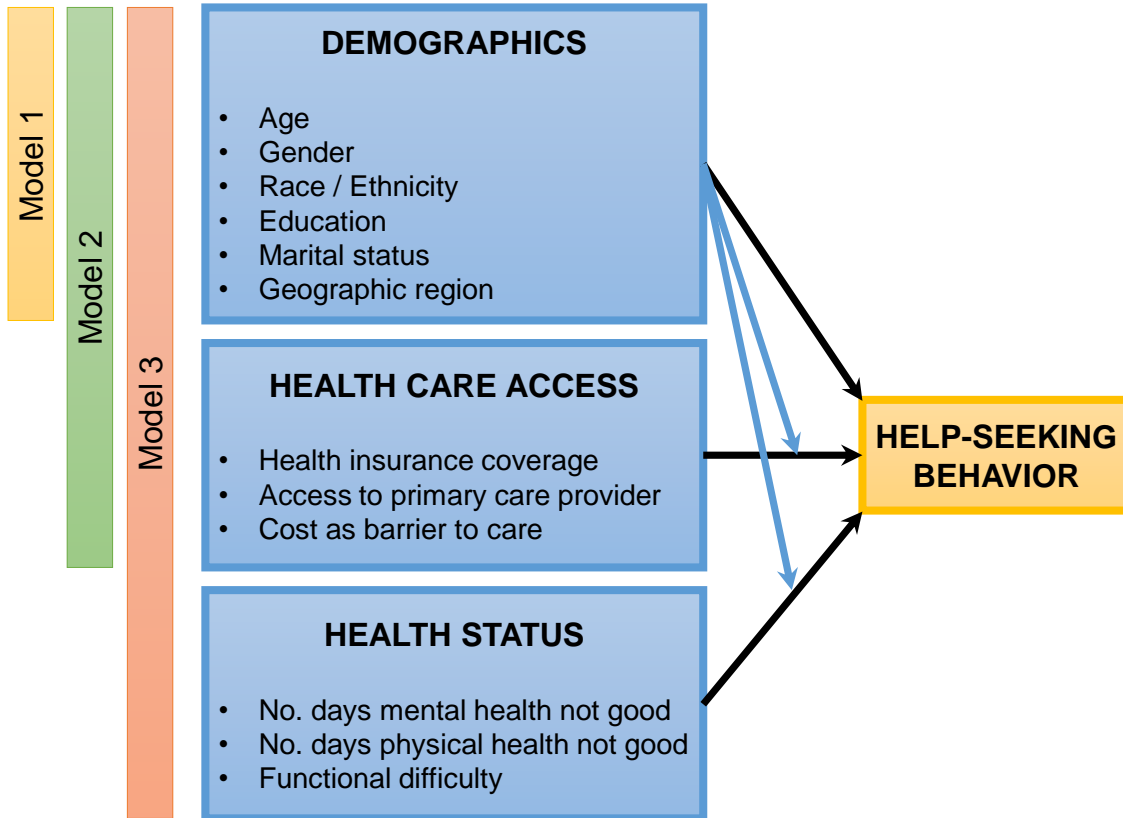
\*\*\* $p < 0.001$ ; \*\* $p < 0.01$ ; \* $p < 0.05$ .

Dependent variable: Help-seeking behavior (1 = sought help, 2 = did not seek help);

Reference category = did not seek help.

Note: Includes imputed missing values for the following variables: education, health insurance, access to primary care provider, cost as a barrier, no. days mental health not good, no. days physical health not good, functional difficulty, and help-seeking behavior

**Figure 4-1:** Conceptual Model for Research Study Question: What is the association between specific demographic factors, health care access, health status, and help-seeking behavior for memory complaints?





**6.** During the past 12 months, how often has confusion or memory loss interfered with your/this person's ability to work, volunteer, or engage in social activities?

- (1) Always
- (2) Usually
- (3) Sometimes
- (4) Rarely
- (5) Never

**7.** During the past 30 days, how often has a family member or friend provided any care or assistance for you/this person because of confusion or memory loss?

- (1) Always
- (2) Usually
- (3) Sometimes
- (4) Rarely
- (5) Never

**8.** Has anyone discussed with a health care professional, increases in your/ this person's confusion or memory loss?

- (1) Yes
- (2) No [End of module]

**9.** Have you/ Has this person received treatment such as therapy or medications for confusion or memory loss?

- (1) Yes
- (2) No

**10.** Has a health care professional ever said that you have/ this person has Alzheimer's disease or some other form of dementia?

- (1) Yes, Alzheimer's Disease
- (2) Yes, some other form of dementia but not Alzheimer's disease
- (3) No diagnosis has been given

\*Note: This module is designed to ask questions #4-10 of the individual who answers the phone or a member of their household. The individual is asked the questions if he/she answers "yes" to question #1. If the individual answers "no" to question #1 then questions #4-10 are asked of a member of the household who is experiencing confusion or memory loss.



## References

- Alzheimer's Association. (2010). 2010 Alzheimer's Disease Facts and Figures. *Alzheimers Dement*, 6(2), 158-194.
- Alzheimer's Association. (2014). 2014 Alzheimer's Disease Facts and Figures. Retrieved from [http://www.alz.org/downloads/Facts\\_Figures\\_2014.pdf](http://www.alz.org/downloads/Facts_Figures_2014.pdf)
- Alzheimer's Association. (2016). 2016 Alzheimer's Disease Facts and Figures. Retrieved from [http://www.alz.org/documents\\_custom/2016-facts-and-figures.pdf](http://www.alz.org/documents_custom/2016-facts-and-figures.pdf)
- Alzheimer's Association and Centers for Disease Control and Prevention. (2013). *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*. Retrieved from <http://www.alz.org/publichealth/downloads/2013-RoadMap.pdf>
- Aminzadeh, F., Byszewski, A., Molnar, F. J., & Eisner, M. (2007). Emotional impact of dementia diagnosis: exploring persons with dementia and caregivers' perspectives. *Aging Ment Health*, 11(3), 281-290.
- Amjad, H., Roth, D. L., Samus, Q. M., Yasar, S., & Wolff, J. L. (2016). Potentially Unsafe Activities and Living Conditions of Older Adults with Dementia. *J Am Geriatr Soc*, 64(6), 1223-1232.
- Bennett, I. M., Chen, J., Soroui, J. S., & White, S. (2009). The contribution of health literacy to disparities in self-rated health status and preventive health behaviors in older adults. *Ann Fam Med*, 7(3), 204-211.
- Berglund, P., & Heeringa, S. (2014). *Multiple Imputation of Missing Data Using SAS*. Cary, NC: SAS Institute, Inc.
- Boise, L., Camicioli, R., Morgan, D. L., Rose, J. H., & Congleton, L. (1999). Diagnosing dementia: perspectives of primary care physicians. *Gerontologist*, 39(4), 457-464.
- Boise, L., Morgan, D. L., Kaye, J., & Camicioli, R. (1999). Delays in the diagnosis of dementia: Perspectives of family caregivers. *Am J Alzheimers Dis Other Demen*, 14(20), 20-26.
- Bradford, A., Kunik, M. E., Schulz, P., Williams, S. P., & Singh, H. (2009). Missed and delayed diagnosis of dementia in primary care: prevalence and contributing factors. *Alzheimer Dis Assoc Disord*, 23(4), 306-314.
- Centers for Disease Control and Prevention. (2013a). About the Behavioral Risk Factor Surveillance System (BRFSS). Retrieved from [http://www.cdc.gov/brfss/about/about\\_brfss.htm](http://www.cdc.gov/brfss/about/about_brfss.htm)
- Centers for Disease Control and Prevention. (2013b). BRFSS Frequently Asked Questions (FAQs). Retrieved from [http://www.cdc.gov/brfss/about/brfss\\_faq.htm](http://www.cdc.gov/brfss/about/brfss_faq.htm)
- Centers for Disease Control and Prevention. (2013c). Self-reported increased confusion or memory loss and associated functional difficulties among adults aged  $\geq 60$  years - 21 States, 2011. *MMWR Morb Mortal Wkly Rep*, 62(18), 347-350.
- Centers for Disease Control and Prevention. (2015). Overview: BRFSS 2011. Retrieved from [http://www.cdc.gov/brfss/annual\\_data/2011/overview\\_11.pdf](http://www.cdc.gov/brfss/annual_data/2011/overview_11.pdf)
- Clark, P. C., Kutner, N. G., Goldstein, F. C., Peterson-Hazen, S., Garner, V., Zhang, R., & Bowles, T. (2005). Impediments to timely diagnosis of Alzheimer's disease in African Americans. *J Am Geriatr Soc*, 53(11), 2012-2017.
- Connell, C. M., Boise, L., Stuckey, J. C., Holmes, S. B., & Hudson, M. L. (2004). Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians. *Gerontologist*, 44(4), 500-507.

- de Vugt, M. E., & Verhey, F. R. (2013). The impact of early dementia diagnosis and intervention on informal caregivers. *Prog Neurobiol*, *110*, 54-62.
- Fitten, L. J., Ortiz, F., & Ponton, M. (2001). Frequency of Alzheimer's disease and other dementias in a community outreach sample of Hispanics. *J Am Geriatr Soc*, *49*(10), 1301-1308.
- Friis, K., Lasgaard, M., Rowlands, G., Osborne, R. H., & Maindal, H. T. (2016). Health Literacy Mediates the Relationship Between Educational Attainment and Health Behavior: A Danish Population-Based Study. *J Health Commun*, *21*(sup2), 54-60.
- Garcia, L. J., McCLeary, L., Emerson, V., Léopoldoff, H., Dalziel, W., Drummond, N., . . . Silvius, J. (2014). The Pathway to Diagnosis of Dementia for Francophones Living in a Minority Situation. *The Gerontologist*, *54*(6), 964-975.
- Hagerty, M. R., Cummins, R. A., Ferriss, A. L., Land, K., Michalos, A. C., Peterson, M., . . . Vogel, J. (2011). Quality of life indexes for national policy: Review and agenda for research. *Social Indicators Research*, *55*, 1-96.
- Hebert, L. E., Weuve, J., Scherr, P. A., & Evans, D. A. (2013). Alzheimer disease in the United States (2010-2050) estimated using the 2010 census. *Neurology*, *80*(19), 1778-1783.
- Hinton, L., Franz, C. E., Reddy, G., Flores, Y., Kravitz, R. L., & Barker, J. C. (2007). Practice constraints, behavioral problems, and dementia care: primary care physicians' perspectives. *J Gen Intern Med*, *22*(11), 1487-1492.
- Hodgson, L. G., & Cutler, S. J. (2004). Help Seeking for Personal Concerns About Developing Alzheimer's Disease. *J Appl Gerontol*, *23*, 385-410.
- Holroyd, S., Turnbull, Q., & Wolf, A. M. (2002). What are patients and their families told about the diagnosis of dementia? Results of a family survey. *Int J Geriatr Psychiatry*, *17*(3), 218-221.
- Hu, S. S., Balluz, L., Battaglia, M. P., & Frankel, M. R. (2011). Improving public health surveillance using a dual-frame survey of landline and cell phone numbers. *Am J Epidemiol*, *173*(6), 703-711.
- Hurt, C. S., Burns, A., Brown, R. G., & Barrowclough, C. (2012). Why don't older adults with subjective memory complaints seek help? *Int J Geriatr Psychiatry*, *27*(4), 394-400.
- Jorm, A. F., Butterworth, P., Anstey, K. J., Christensen, H., Eastaer, S., Maller, J., . . . Sachdev, P. (2004). Memory complaints in a community sample aged 60-64 years: associations with cognitive functioning, psychiatric symptoms, medical conditions, APOE genotype, hippocampus and amygdala volumes, and white-matter hyperintensities. *Psychol Med*, *34*(8), 1495-1506.
- Knopman, D., Donohue, J. A., & Gutterman, E. M. (2000). Patterns of care in the early stages of Alzheimer's disease: impediments to timely diagnosis. *J Am Geriatr Soc*, *48*(3), 300-304.
- Kotagal, V., Langa, K. M., Plassman, B. L., Fisher, G. G., Giordani, B. J., Wallace, R. B., . . . Foster, N. L. (2015). Factors associated with cognitive evaluations in the United States. *Neurology*, *84*(1), 64-71.
- Lathren, C. R., Sloane, P. D., Hoyle, J. D., Zimmerman, S., & Kaufer, D. I. (2013). Improving dementia diagnosis and management in primary care: a cohort study of the impact of a training and support program on physician competency, practice patterns, and community linkages. *BMC Geriatr*, *13*, 134.
- Lehmann, S. W., Black, B. S., Shore, A., Kasper, J., & Rabins, P. V. (2010). Living alone with dementia: lack of awareness adds to functional and cognitive vulnerabilities. *Int Psychogeriatr*, *22*(5), 778-784.

- Leung, K. K., Finlay, J., Silvius, J. L., Koehn, S., McCleary, L., Cohen, C. A., . . . Drummond, N. (2011). Pathways to diagnosis: Exploring the experiences of problem recognition and obtaining a dementia diagnosis among Anglo-Canadians. *Health & Social Care in the Community*, 19(4), 372-381.
- Low, L. F., Anstey, K. J., Lackersteen, S. M. P., & Camit, M. (2011). Help-seeking and service use for dementia in Italian, Greek and Chinese Australians. *Aging & Mental Health*, 15(3), 397-404.
- McCleary, L., Persaud, M., Hum, S., Pimlott, N. J. G., Cohen, C. A., Koehn, S., . . . Drummond, N. (2013). Pathways to dementia diagnosis among South Asian Canadians. *Dementia*, 12(6), 769-789.
- Millard, F., & Baune, B. (2009). Dementia - who cares? A comparison of community needs and primary care services. *Australian Family Physician*, 38(8), 642-+.
- Milne, A. J., Woolford, H. H., Mason, J., & Hatzidimitriadou, E. (2000). Early diagnosis of dementia by GPs: an exploratory study of attitudes. *Aging & Mental Health*, 4(4), 292-300.
- Morgan, D. G., Walls-Ingram, S., Cammer, A., O'Connell, M. E., Crossley, M., Bello-Haas, V. D., . . . Stewart, N. (2014). Informal caregivers' hopes and expectations of a referral to a memory clinic. *Social Science & Medicine*, 102, 111-118.
- Morhardt, D., Pereyra, M., & Iris, M. (2010). Seeking a diagnosis for memory problems: the experiences of caregivers and families in 5 limited English proficiency communities. *Alzheimer Dis Assoc Disord*, 24 Suppl, S42-48.
- Moyer, V. A., & U. S. Preventive Services Task Force. (2014). Screening for cognitive impairment in older adults: U.S. Preventive Services Task Force recommendation statement. *Ann Intern Med*, 160(11), 791-797.
- Mukadam, N., Cooper, C., Basit, B., & Livingston, G. (2011). Why do ethnic elders present later to UK dementia services? A qualitative study. *Int Psychogeriatr*, 23(7), 1070-1077.
- National Institute on Aging. (2014). Alzheimer's Disease Medications Fact Sheet. Retrieved from <http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-medications-fact-sheet>
- Pentzek, M., Wollny, A., Wiese, B., Jessen, F., Haller, F., Maier, W., . . . AgeCoDe Study, G. (2009). Apart from nihilism and stigma: what influences general practitioners' accuracy in identifying incident dementia? *Am J Geriatr Psychiatry*, 17(11), 965-975.
- Pires, C., Silva, D., Maroco, J., Gino, S., Mendes, T., Schmand, B. A., . . . de Mendonca, A. (2012). Memory complaints associated with seeking clinical care. *Int J Alzheimers Dis*, 2012, 725329.
- Ploeg, J., Denton, M., Tindale, J., Hutchison, B., Brazil, K., Akhtar-Danesh, N., . . . Plenderleith, J. M. (2009). Older adults' awareness of community health and support services for dementia care. *Canadian Journal on Aging*, 28(4), 359-370.
- Ramakers, I. H., Visser, P. J., Bittermann, A. J., Ponds, R. W., van Boxtel, M. P., & Verhey, F. R. (2009). Characteristics of help-seeking behaviour in subjects with subjective memory complaints at a memory clinic: a case-control study. *Int J Geriatr Psychiatry*, 24(2), 190-196.
- Relkin, N. (2000). Screening and early diagnosis of dementia. *Am J Manag Care*, 6(22 Suppl), S1111-1118; discussion S1119-1124.

- Samsi, K., Abley, C., Campbell, S., Keady, J., Manthorpe, J., Robinson, L., . . . Bond, J. (2014). Negotiating a Labyrinth: experiences of assessment and diagnostic journey in cognitive impairment and dementia. *International Journal of Geriatric Psychiatry*, 29(1), 58-67.
- SAS Institute. (2013). *SAS 9.4 language reference concepts*. Retrieved from <http://www.books24x7.com/marc.asp?bookid=62815>
- Turner, S., Iliffe, S., Downs, M., Wilcock, J., Bryans, M., Levin, E., . . . O'Carroll, R. (2004). General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia. *Age Ageing*, 33(5), 461-467.
- U.S. Department of Health and Human Services. (2016). National Plan to Address Alzheimer's Disease: 2016 Update. Retrieved from <https://aspe.hhs.gov/sites/default/files/pdf/205581/NatlPlan2016.pdf>
- Waldorff, F. B., Rishoj, S., & Waldemar, G. (2008). If you don't ask (about memory), they probably won't tell. *J Fam Pract*, 57(1), 41-44.
- Weimer, D. L., & Sager, M. A. (2009). Early identification and treatment of Alzheimer's disease: social and fiscal outcomes. *Alzheimers Dement*, 5(3), 215-226.
- Werner, P. (2003a). Factors influencing intentions to seek a cognitive status examination: a study based on the Health Belief Model. *Int J Geriatr Psychiatry*, 18(9), 787-794.
- Werner, P. (2003b). Knowledge about symptoms of Alzheimer's disease: Correlates and relationships to help-seeking behavior. *International Journal of Geriatric Psychiatry*, 18, 1029-1036.
- World Health Organization. (2012). Dementia: A public health priority. Retrieved from [http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1)

## **CHAPTER 5**

### **Conclusion**

Despite the potential advantages of early AD diagnosis and intervention, many older adults experiencing memory problems do not seek timely assistance from a doctor. National and state-led efforts to promote early AD detection and diagnosis may generate greater awareness about the benefits of early, accurate diagnosis, as well as improvements in the care and support received by patients and families. However, an increased emphasis on early diagnosis and screening could also result in heightened perceived AD threat in healthy individuals, potentially leading to overdiagnosis and overconsumption of the health care system. While this dissertation does not seek to generate evidence regarding potential benefits and harms of early cognitive assessment and intervention, or examine the diagnostic process beyond initial contact with a doctor, it does provide information on specific factors that may underlie the help-seeking process that health care providers and policy makers should consider in their efforts to increase early identification and timely diagnosis.

To map the present state of our understanding of factors that may influence the decision to seek help for memory complaints among older adults, this dissertation begins with a systematic review of the current literature (Chapter 2). Important factors related to formal help-seeking variables and outcomes that emerged from this review as salient include demographic characteristics, knowledge, beliefs and personal experiences, psychosocial factors, cognitive and disease-related factors, and health care policies, access and services. Findings from this review

suggest that these factors are multi-layered with individual, interpersonal and structural/policy level factors each playing a role in the decision to seek help. The review also helped to inform my conceptual model and identified several important gaps/limitations in the literature, which this dissertation seeks to address.

Chapters 3 and 4 focus on bridging gaps identified in the literature review by empirically examining several understudied constructs that may influence help-seeking behavior. Chapter 3 investigates psychosocial and cognitive factors related to perceived AD threat, a predictor of health-related action, while Chapter 4 examines demographic, health care access, and health status predictors of help-seeking behavior among older adults with memory concerns. By using population-based samples of older adults from the Health and Retirement Study and the Behavioral Risk Factor Surveillance System, this dissertation also addresses the need for larger, population-based or nationally representative studies on formal help-seeking behavior with racially and ethnically diverse samples that can offer cross-group comparisons. In doing so, this dissertation moves beyond much of the work previously conducted on the role these factors play in the decision to seek help among older Americans experiencing memory problems.

The findings in Chapter 3 showed that among the general adult population, perceived AD threat was associated with age, personal experience with AD, beliefs about stress and genetics as AD risk factors, depressive symptoms, subjective memory complaints, and cognitive function. These results demonstrate that perceived AD threat is not just a function of an individual's cognitive impairment, but a response to a complex set of determinants that include personal beliefs and experiences, and psychological well-being. While this study does not examine the association between perceived AD threat and health actions, perceived AD threat may affect a range of behaviors including the decision to seek medical help.

Factors that emerged from the analysis in Chapter 4 as significantly associated with help-seeking included race/ethnicity, education level, access to a primary care provider, mental health status, and functional difficulty. These findings suggest that help-seeking occurs when significant memory problems interfere with independent function and daily activities, and when quality of life as it relates to mental health begins to be affected. The results of this study also capture a snapshot of factors that may influence formal help-seeking behavior at the time when free cognitive evaluations became available as part of the Medicare Annual Wellness Visit. A clear majority of respondents reporting increased confusion and memory loss had not sought help from a health care professional (80%), suggesting that, despite increased access to cognitive evaluations through the Medicare Annual Wellness Visit, there is still much work to be done.

Using two large, population-based data sets in both empirical chapters, I was able to corroborate some of the findings from smaller-scale studies. For instance, my findings that personal experience with AD, depressive symptoms, and cognitive function are related to perceived AD threat are, for instance, consistent with prior research (L. G. Hodgson & Cutler, 1997; Suhr & Kinkela, 2007), as are the findings that functional difficulty and education level are significantly associated with help-seeking behavior (L.G. Hodgson & Cutler, 2004; Ramakers et al., 2009). While the use of secondary data did not allow me to examine the relationship between perceived AD threat and help-seeking behavior in the two empirical studies, there is a well-established theoretical and empirical basis for the link between perceived threat and health action (Becker, 1974; Champion & Skinner, 2008; Janz & Becker, 1984). In the area of help-seeking for memory concerns among older adults, this remains an important area for future study.

One of the difficulties of working with secondary survey data is, of course, the fact that the questionnaire measures are not specifically designed for one's own study. Several of the measures employed in the two empirical studies lacked specificity and context for interpretation. For instance, in the BRFSS study, the measure of mental health did not specify what problems respondents had encountered in the last month and whether this was related to their memory problems or concerns. The measure for help-seeking behavior also did not provide context as to who discussed the concerns with the doctor, when the concerns were discussed, and whether the person was further evaluated or diagnosed as an outcome of the conversation. The absence of reliable and validated measures for help-seeking behavior is a much broader problem, given that the vast majority of studies identified in the systematic review relied on investigator generated, single item measures of help-seeking. The development, validation, and use of standardized measures of help-seeking are needed for cross-study comparisons and to move research findings into practice. In the HRS study, the use of shortened scales in the experimental module did not allow for an in-depth examination of certain factors, like AD knowledge and perceived AD threat. The two items used for AD knowledge may not reflect the full range of an individual's understanding or knowledge about Alzheimer's disease. There were also several constructs identified in the systematic review as possible predictors of formal help-seeking behavior that were absent from the two data sets. It would have been informative, for instance, to examine the associations between help-seeking behavior and social support, stigma, and perceived benefits/barriers of diagnosis. We know very little about how support from family members, caregivers, or others may have factored into the decision to discuss concerns with a doctor. Did disease stigma play a role in preventing help-seeking, or were people more likely to seek help if they perceived early diagnosis to be personally beneficial? There are still many questions left



unanswered. Despite these limitations, the two databases used in my dissertation analyses were fortuitous in that the measures included in these databases did address many aspects of my research questions.

The findings of the two empirical studies have implications for health care professionals working with older adults. First, there is a clear need to educate physicians about the importance of discussing memory concerns with their older adult patients. There is still ambivalence about the value of early dementia diagnosis in the medical community due to concerns about causing patient distress and harm (Boise, Camicioli, Morgan, Rose, & Congleton, 1999; Millard & Baune, 2009; Milne, Woolford, Mason, & Hatzidimitriadou, 2000). Physicians need to understand that early diagnosis disclosure can facilitate choice, autonomy, and future planning, and that the act of withholding diagnostic information may have serious implications for patient health and safety.

Second, the findings also point to the need for careful initial screening of individuals who present with memory concerns, with objective measures of cognitive functioning as well as the consideration of factors like family experience with AD and depressive symptoms. Self-reported memory complaints are not always indicative of cognitive impairment or dementia (Alladi, Arnold, Mitchell, Nestor, & Hodges, 2006), and it is important that physicians conduct a thorough evaluation of actual cognitive decline. Patients may also be worried about developing dementia because of a family member with the disease, or experiencing cognitive problems due to depression or other underlying causes. There are clear criteria for the diagnosis of AD, and there is also evidence that some clinical screening instruments may be especially useful and accurate for diagnosing cognitive impairment (Moyer & U. S. Preventive Services Task Force, 2014). Yet, there is no widely adopted clinical algorithm or standardized method for the

detection and evaluation of dementia. We know very little about what methods and tools are currently being used in primary care settings across the U.S. (Cordell et al., 2013). To prevent the harms of both under- and over-diagnosis, we need to develop more standardized tools and methods for diagnosing patients that take into account factors related to perceived AD threat and help-seeking behavior that may make a patient more or less likely to raise concerns during a clinical visit.

Third, primary care providers often viewed by patients as the first point of formal contact for discussing cognitive or memory changes (Leung et al., 2011; Low, Anstey, Lackersteen, & Camit, 2011; McCleary et al., 2013; Ploeg et al., 2009; Samsi et al., 2014; Werner, 2003), and they play a critical role in the process of dementia diagnosis and referral. Primary care providers thus need to be aware of existing disparities in diagnosis as well as the personal and social barriers to raising memory concerns with a provider. To overcome some of these barriers, it may be necessary for physicians to make conversational inquiries with patients and family members about memory concerns, functional difficulties, and dementia-related symptoms during routine visits.

The study findings also have implications for public education efforts. First, given the importance of personal beliefs and experiences to perceived AD threat, and the fact that most respondents reporting increased memory loss had not sought help, public education campaigns should focus on: 1) the benefits of early detection and diagnosis, 2) distinguishing between the early signs of dementia and mild cognitive changes that occur as part of normal aging, 3) the availability of prevention and treatment options, and 4) the diagnostic process, including when and how to seek help and what to expect during and after the clinical evaluation. In addition,

education efforts aimed at reducing the pervasive stigma attached to older adults with dementia is an important area for facilitating help-seeking and improving early detection and diagnosis.

Second, the finding that having a spouse or first degree relative with AD was related to higher perceived AD threat suggests a need to offer education and support to family members who may be concerned about their own susceptibility to the disease. As the prevalence of AD rises in the coming years, more people will have experience with a family member who has the disease. This may lead to increased levels of perceived threat in healthy individuals. Patients who present to their doctor with memory complaints, who are already worried about AD due to a family member who has the disease, may be more likely to have inaccurate perceptions of their own cognitive functioning. A moderate level of perceived AD threat may be necessary in motivating older adults to seek help for concerns about cognitive changes, but high levels of perceived AD threat may potentially lead to unnecessary and frequent health care visits, misdiagnosis, or other harms. In future studies, it would be informative to examine the conditions under which perceived AD threat may either benefit or adversely affect patients and health care systems.

This body of work also provides a foundation for several new avenues of research. First, as noted in the systematic literature review, there is a dearth of longitudinal research studies on help-seeking for memory concerns and dementia symptoms. It would be illuminating to explore factors involved in the help-seeking process across time as cognitive function declines. Fluctuations in perceived AD threat and its relationships with other variables could also be examined over time, as could the link between perceived AD threat and help-seeking behavior and health outcomes. Second, the development of a valid and reliable measure of help-seeking for memory concerns is an important area for future study. A standardized help-seeking measure

would enable replication of findings and enhance cross-study comparisons. Third, there were several factors identified in the systematic literature review as important to help-seeking behavior that I was unable to investigate in the two empirical studies. Future research should examine the relationship between these factors—including disease stigma, social support, and perceived benefits and barriers to diagnosis—and help-seeking behavior among older adult and caregiver populations. Future studies may also want to examine help-seeking behavior as it relates to health care access barriers that were not explored in this study that may be especially relevant for older adult populations, such as availability of transportation to medical appointments. Fourth, because access to a health care provider was found to be a significant predictor of help-seeking, it would also be informative to identify and define aspects of the patient-provider relationship that may facilitate or create barriers to help-seeking. This could involve administering survey questionnaires to both primary care providers and their patients to explore attitudes, beliefs, and perceptions that may influence the help-seeking and diagnostic process, as well as observational studies with assessment of patient-provider communication around dementia across practice settings. Lastly, given that in my study there were no significant differences in help-seeking behavior for Hispanic and non-Hispanic Blacks reporting increased memory loss compared to non-Hispanic Whites, suggests that future studies examining racial/ethnic disparities in diagnoses of dementia would do well to focus on structural or health care system related factors rather than individual behaviors. Factors such as racial and ethnic discrimination in health care settings, poverty and lack of access to resources, and a lack of culturally competent health care providers, should be explored in relation to receiving a dementia diagnosis.

Dementia is undoubtedly an important concern for many older adults, and the ability to seek help from a health care provider and receive proper assessment, care, and support is paramount. Research, such as that undertaken in this dissertation, seeking to understand factors associated with the help-seeking response, including those that determine one's level of perceived AD threat, provides an essential starting point for the development of decision-making models and interventions aimed at addressing barriers to timely AD diagnosis and treatment.

## References

- Alladi, S., Arnold, R., Mitchell, J., Nestor, P. J., & Hodges, J. R. (2006). Mild cognitive impairment: applicability of research criteria in a memory clinic and characterization of cognitive profile. *Psychol Med*, *36*(4), 507-515.
- Becker, M. H. (1974). The Health Belief Model and Personal Health Behavior. *Health Education Monographs*, *2*, 324-473.
- Boise, L., Camicioli, R., Morgan, D. L., Rose, J. H., & Congleton, L. (1999). Diagnosing dementia: perspectives of primary care physicians. *Gerontologist*, *39*(4), 457-464.
- Champion, V. L., & Skinner, C. S. (2008). The Health Belief Model. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health Behavior and Health Education* (pp. 45-62). San Francisco, CA.
- Cordell, C. B., Borson, S., Boustani, M., Chodosh, J., Reuben, D., Verghese, J., . . . Medicare Detection of Cognitive Impairment, W. (2013). Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting. *Alzheimers Dement*, *9*(2), 141-150.
- Hodgson, L. G., & Cutler, S. J. (1997). Anticipatory dementia and well-being. *Am J Alzheimers Dis Other Demen*, *12*, 62-66.
- Hodgson, L. G., & Cutler, S. J. (2004). Help Seeking for Personal Concerns About Developing Alzheimer's Disease. *J Appl Gerontol*, *23*, 385-410.
- Janz, N. K., & Becker, M. H. (1984). The Health Belief Model: a decade later. *Health Educ Q*, *11*(1), 1-47.
- Leung, K. K., Finlay, J., Silvius, J. L., Koehn, S., McCleary, L., Cohen, C. A., . . . Drummond, N. (2011). Pathways to diagnosis: Exploring the experiences of problem recognition and obtaining a dementia diagnosis among Anglo-Canadians. *Health & Social Care in the Community*, *19*(4), 372-381.
- Low, L. F., Anstey, K. J., Lackersteen, S. M. P., & Camit, M. (2011). Help-seeking and service use for dementia in Italian, Greek and Chinese Australians. *Aging & Mental Health*, *15*(3), 397-404.
- McCleary, L., Persaud, M., Hum, S., Pimlott, N. J. G., Cohen, C. A., Koehn, S., . . . Drummond, N. (2013). Pathways to dementia diagnosis among South Asian Canadians. *Dementia*, *12*(6), 769-789.
- Millard, F., & Baune, B. (2009). Dementia - who cares? A comparison of community needs and primary care services. *Australian Family Physician*, *38*(8), 642-+.
- Milne, A. J., Woolford, H. H., Mason, J., & Hatzidimitriadou, E. (2000). Early diagnosis of dementia by GPs: an exploratory study of attitudes. *Aging & Mental Health*, *4*(4), 292-300.
- Moyer, V. A., & U. S. Preventive Services Task Force. (2014). Screening for cognitive impairment in older adults: U.S. Preventive Services Task Force recommendation statement. *Ann Intern Med*, *160*(11), 791-797.
- Ploeg, J., Denton, M., Tindale, J., Hutchison, B., Brazil, K., Akhtar-Danesh, N., . . . Plenderleith, J. M. (2009). Older adults' awareness of community health and support services for dementia care. *Canadian Journal on Aging*, *28*(4), 359-370.
- Ramakers, I. H., Visser, P. J., Bittermann, A. J., Ponds, R. W., van Boxtel, M. P., & Verhey, F. R. (2009). Characteristics of help-seeking behaviour in subjects with subjective memory

- complaints at a memory clinic: a case-control study. *Int J Geriatr Psychiatry*, 24(2), 190-196.
- Samsi, K., Abley, C., Campbell, S., Keady, J., Manthorpe, J., Robinson, L., . . . Bond, J. (2014). Negotiating a Labyrinth: experiences of assessment and diagnostic journey in cognitive impairment and dementia. *International Journal of Geriatric Psychiatry*, 29(1), 58-67.
- Suhr, J. A., & Kinkela, J. H. (2007). Perceived threat of Alzheimer disease (AD): the role of personal experience with AD. *Alzheimer Dis Assoc Disord*, 21(3), 225-231.
- Werner, P. (2003). Knowledge about symptoms of Alzheimer's disease: Correlates and relationships to help-seeking behavior. *International Journal of Geriatric Psychiatry*, 18, 1029-1036.