

DEMENTIA WORRY: DOES PUBLIC STIGMA PREDICT PEOPLE'S CONCERNS  
ABOUT DEVELOPING DEMENTIA

A Thesis  
by  
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Submitted to the School of Graduate Studies  
at Appalachian State University  
in partial fulfillment of the requirements for the degree of  
MASTER OF ARTS

August 2022  
Department of Psychology

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## **Abstract**

### DEMENTIA WORRY: DOES PUBLIC STIGMA PREDICT PEOPLE’S CONCERNS ABOUT DEVELOPING DEMENTIA

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Dementia worry is “An emotional response to the perceived threat of developing dementia” (Kessler et al., 2012, p. 277). The greater this worry is, the poorer one’s quality of life tends to be. The behavioral changes seen in many dementia cases can lead the public to think people with dementia are dangerous and create greater public stigma and distance between those with and without dementia. Previous research indicates a relationship between increased dementia worry and anticipated stigma concerning attitudes from friends and family. The stereotype content model describes two dimensions underlying how we stereotype people that are not part of our group: their status in society (“competence”) and their interdependence (“warmth”). Prior work on stereotyping of both people with dementia and older adults finds that people perceive these groups as being “warm but incompetent.” This study hypothesized that people’s anticipated stigma about developing dementia would be greatest in domains that focus on being competent (e.g., work) and smallest in domains that focus on being warm (e.g., family). In addition, the relationship between anticipated stigma and worry should be greater for work-based stigma than family-based stigma. Using a within-subjects, correlational design that looked

at the relationships between anticipated stigma and dementia worry, participants completed surveys to assess their attitudes on anticipated stigma from friends and family, work colleagues, and healthcare professionals should they be diagnosed with dementia, as well as questions about warmth and competence, and a dementia worry scale to evaluate the dismissability and controllability of thoughts about both developing and having dementia. Overall, the results fully supported the first hypothesis and partially supported the second hypothesis. The results are consistent with those of previous research, in that anticipated stigma was a significant predictor of dementia worry even when accounting for other factors. These results suggest that competence plays a key role in anticipated stigma from work colleagues. Furthermore, threat appraisals produced for the work domain due to the stereotype that people with dementia are perceived to have low competency were in fact, greater than those produced in the friends and family domain.

## **Acknowledgments**

I wish to thank my mentor, Dr. Lisa Emery for being there for me every step of the way. From guiding me over Zoom for the entire first year towards research avenues that eventually culminated in the current research question, to helping me through grant proposals and budgeting concerns face-to-face during my second year, none of this would have been possible without her. Dr. Emery helped me over countless writing hurdles, including ones that demonstrate that I still struggle with being concise. I hope this thesis can be the beginning of fewer wordy sentences in my future projects. I also want to take this time to thank my committee members, Dr. Doris Bazzini and Dr. Lisa Curtin who helped shape this project into its final form. Their expertise and insight allowed me to incorporate measures I hadn't initially thought to, in turn making my results that much more meaningful. Finally, I want to thank my family and friends who were there for me through this entire project and sat patiently while I enthusiastically yelled about false negatives I found in existing literature. I wouldn't have been able to do any of this to the level I have without anyone listed here; this is my sincerest thank you to everyone involved even a small amount.

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**Dementia worry: Does public stigma predict people's concerns about developing dementia?**

As the population of older adults in the United States increases, so too does the threat of dementia in society on a larger scale. As of 2022, the American Psychiatric Association estimated that dementia affects about 1-2% of individuals aged 65 and as high as 30% of individuals aged 85 and older, demonstrating an exponential increase as chronological age increases (American Psychiatric Association, 2022). As of 2020, there were 5.8 million Alzheimer's dementia cases alone in the United States, with the number projected to increase to as high as 13.8 million by 2050 (Alzheimer's Association, 2020).

With the prevalence of dementia increasing at exponential rates, similar increases in dementia worry may also occur. Dementia worry is a person's emotional response to a perceived threat of developing dementia (Kessler et al., 2012). Part of this worry may stem from knowledge that the time course of Alzheimer's disease, the most common form of dementia, can last for as long as 10 years, depending on the individual (American Psychiatric Association, 2013). Other explanations of dementia worry may be attributed to knowledge of dementia symptoms and the subsequent stigma that dementia carries with it. For example, one recent study of middle-aged and older adults (Maxfield & Greenberg, 2021) found that dementia worry was greater in people who indicated that they would anticipate greater stigmatizing behaviors from family members were they to be diagnosed with dementia in the future.

One way of conceptualizing the relationship between dementia worry and anticipated stigma is through the stereotype content model (SCM) developed by Fiske et al. (1999). The SCM focuses on the positive and negative facets of how members of stereotyped groups are sorted: through their status in society (incompetent vs. competent) and through their interdependence (cold vs. warm). Prior research has found that stereotypes of people with

Alzheimer's disease, much like those of older adults in general, portray them as "warm but incompetent" (Sadler et al., 2012, p. 920). This suggests that dementia worry should be greatest in contexts where competence is particularly important (e.g., work relationships) than where warmth is more important (e.g., family relationships).

In the current study, I investigated the relationship between dementia worry and anticipated stigma. Middle-aged adults (ages 40-64) were targeted in the study, as they are typically still in the workforce, involved with caring for parents who might have the disease, and are often targets of age-discrimination at work (Hanrahan et al., 2017). Below, I will first review what dementia is, and what factors have previously been associated with increased dementia worry. I will then review what is known about stigma and stereotyping, within the context of dementia and aging. Finally, I will discuss the Stereotype Content model as a framework for predicting relationships between stigma and dementia worry.

## **Dementia**

Dementia is a term that has become familiar to many people and is often equated with 'memory loss.' While memory loss is a large part of dementia diagnoses, the concept of dementia extends far beyond one losing their memories and the ability to form new ones. Dementia is typically used as an umbrella term for a family of diseases such as Alzheimer's disease, Vascular dementia, Frontotemporal dementia, Lewy-Body dementia, and Parkinson's disease dementia, and is known as a major neurocognitive disorder within the *Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> edition, Text Revision [DSM-5-TR]* (American Psychiatric Association, 2022).

These diseases impact virtually every part of the brain in one way or another, including complex attention, executive function, learning and memory, language, perceptual-motor

processes, or social cognitive areas (American Psychiatric Association, 2022).

Like most mental illnesses, an individual must meet a certain threshold for a dementia diagnosis, which includes cognitive declines in one or more cognitive domains discussed above, as well as concerns from a knowledgeable informant, such as a spouse, family member, or close friend, and either subpar performance on an objective assessment or a marked decline over time. While memory is certainly a salient example of cognitive issues, other cognitive concerns that may be of note for a potential dementia diagnosis include difficulty with following the plot of a television show or difficulty with executive tasks such as resuming a task after being interrupted or planning a future event (American Psychiatric Association, 2013).

With the exception of Frontotemporal dementia, which presents symptoms warranting diagnosis in an individual from ages 40-65, most types of dementia such as Alzheimer's disease (AD) are more common in individuals 65 and older (American Psychiatric Association, 2022; Johns Hopkins Medicine, 2021). Younger individuals in their 50s and early 60s who develop symptoms of AD are referred to as having "early onset" form, also referred to as "familial AD" due to the strong genetic link often related to known dominantly-inherited gene mutations. The more common "late onset" form of AD also has some genetic links. One specific mutation known to significantly increase an individual's risk of developing Alzheimer's disease is being homozygous for the apolipoprotein E4 allele that transports cholesterol in the blood.

Although dementia diagnoses tend to be most common after age 65, the underlying disease processes are thought to begin much sooner. For example, the last decade has seen the addition of "Mild Neurocognitive Disorder" to the DSM-5, which is more commonly called "Mild Cognitive Impairment" (MCI) in the medical literature. People with MCI are more likely than those without MCI to convert to AD, particularly if their cognitive impairment is in the

memory domain (Yaffe et al., 2006). In addition, the development of biomarkers for AD has led to an understanding that the accumulation of beta-amyloid, a key protein that is present in large concentrations in the brains of people with AD, begins many decades before a diagnosis of Alzheimer's disease, when people are in their 30s or 40s (Jack et al., 2013).

Currently, most medications that exist for the specific treatment of dementia, such as acetylcholinesterase inhibitors, only treat the symptoms rather than slowing down degeneration (Kessler et al., 2012). Although the FDA recently gave accelerated approval to a drug that targets beta-amyloid, its effectiveness for preventing cognitive decline is not clear, and its approval has led to significant controversy (Mullard, 2021). Because of the lack of treatment options, some individuals express apathy towards consulting medical specialists, in one instance saying: "There's not much point going to your doctor, really is there, I mean it's not like they can cure it or anything" (Corner & Bond, 2004, p. 149).

### **Dementia Worry**

The increased prevalence of AD, combined with a lack of effective treatments, can lead to increased worry about developing the disease. Kessler et al. (2012) call this concern "dementia worry." Kessler et al. define dementia worry as, "An emotional response to the perceived threat of developing dementia, independent of chronological age and cognitive status" (p. 277). Researchers have found that greater dementia correlates with poorer quality of life. Arguably, a bit of worry is good and can serve as a motivator to drive someone to get routine evaluations, communicate with their primary care physician, and monitor their own cognitive processes, whereas too much worry might prevent someone from seeking medical help due to immense fear of their suspicions being confirmed.

Several factors may influence an individual's levels of dementia worry, including

exposure to the disease itself through friends and family members (Kessler et al., 2012). Having a first-degree family member (parent or sibling) is associated with higher worry about developing AD, compared to individuals who do not know anyone with the diagnosis (Corner & Bond, 2004; Cutler, 2015). Family exposure appears to be the most salient predictor of dementia worry throughout the literature, though exposure to individuals with dementia who are not family members has still been seen to significantly contribute towards dementia worry, as noted by Kinzer and Suhr (2016). This suggests that a combination of genetic risk and knowledge of the disease raises worries about developing dementia.

Education may also play a role in the elevation of dementia worry, though it is controversial to an extent (Cutler & Hodgson, 2001). Cutler and Hodgson surveyed middle-aged, adult children with and without familial history of AD. They found that not only were individuals with first-degree relatives more worried about their own futures but that those with higher educational attainment on top of their familial history demonstrated a further increased worry. Individuals with higher educational attainment and *no* familial history appeared to demonstrate lower levels of worry. Cutler and Hodgson (2001) hypothesized that this relationship may be due to the idea that highly educated individuals may be aware that familial AD can be associated with early onset of the disease. Therefore, these adults who have the familial connection, may see themselves as particularly vulnerable to the disease, even in middle age. In contrast, the participants who had no evidence of a familial link, might have known that sporadic AD is more likely to occur in older age, and therefore did not see themselves as especially vulnerable at their current age. The idea that education is a significant predictor of dementia worry has been contested. While Cutler and Hodgson (2001) found a significant interaction between education and family history, Cutler (2015) conducted a similar study and

found no such effect.

Another factor linked to higher levels of dementia worry is subjective memory (Kessler et al., 2012). Because memory tends to be the part of cognition most associated with dementia, it is not surprising that most people would monitor and notice changes in it first. Kinzer and Suhr (2016) found that individuals who exhibited higher dementia worry demonstrated more subjective memory issues than those individuals who had low dementia worry. Similarly, those individuals whose greater subjective memory complaints and dementia worry showed memory concern scores that were comparable to individuals who had medically diagnosed objective memory issues. Further research has suggested that individuals with subjective memory complaints may be at a greater risk for developing mild cognitive impairment, and dementia later still; a continued poor assessment of one's own subjective memory may negatively impact their worry (Cutler, 2015).

### **Stigma and Age-based Stereotyping**

One factor that has only recently been investigated as a contributor to dementia worry is the stigma that people anticipate from a diagnosis of the disorder (Maxfield & Greenberg, 2021). Although the impact of stigma on help-seeking for mental health disorders has been well-studied (e.g., Corrigan et al., 2014; Garland et al., 2009; Nolan et al., 2006; Vogel et al., 2013), a dementia diagnosis differs in many ways from a traditional mental illness diagnosis. As a primarily neurological disorder that is diagnosed in later life, it can be difficult to disentangle disease-specific stigma from the broader age-related stigma seen in Western cultures. Therefore, below I will discuss what is known about stigma and mental illness, dementia-specific stigma, and Ageism more generally. Because culture impacts attitudes about both mental health and aging, I will include a discussion of cross-cultural research on these topics.

**Stigma and its Consequences.** The most widely accepted definition of stigma defines it as “an attribute that deeply discredits and lowers the status of an individual from a normal person to a person with whom something is wrong” (Goffman, 1963 as cited in Kessler et al., 2012, p. 278). Most stigma research differentiates between public-stigma and self-stigma. Both types of stigma involve aspects of stereotyping, prejudice, and discrimination. Stereotyping involves negative beliefs about a group of individuals (e.g., incompetent, unpredictability), prejudice involves the often-negative emotion-driven agreement with a belief or reaction (e.g., fear), and discrimination involves the behavioral manifestation of that prejudice (e.g., isolation, avoidance). Public stigma refers to how these attitudes and behaviors are directed at a specific social group, whereas self-stigma refers to internalization of public stigma among the members of the stigmatized group (Nguyen & Li, 2020; Vogel et al., 2013).

Public- and self-stigma occur in conjunction with each other in most instances, though depending on the levels of prejudice, stereotyping, and discrimination occurring with public stigma, the severity of the self-stigma may not be as severe (Vogel et al., 2013). Large-scale negative perceptions about people with dementia may create fear and discrimination (Nguyen & Li, 2020; Vogel et al., 2013). As a result of this fear, people with a diagnosis of dementia often internalize those attributions and may, in turn, have lower self-esteem, and withdraw from social events and self-isolate from both strangers and loved ones. Indeed, public- and self-stigma are so intertwined that Vogel et al. (2013) found that higher initial public stigma against individuals seeking help predicted subsequently higher self-stigma, though higher initial self-stigma did not predict higher public-stigma. Therefore, as a result of public-stigma, further misconceptions about dementia and old age may lead to internalization that impacts fear of the unknown, aging, and one’s own competence (Graham et al., 2003).



Stigma surrounding severe mental illness can lead to significant barriers in functioning, help-seeking, and diagnosis (Corrigan et al., 2014). Two main barriers, person-level and provider/system-level, can make it difficult for people with severe mental illness to seek help. Person-level barriers involve attitudes and behaviors that lead to avoiding or dropping out of treatment prematurely because of a lack of support or belief in its ineffectiveness. Provider and system-level barriers include a lack of insurance, staff and cultural incompetence, and even workforce limitations (Corrigan et al., 2014). These provider- and system-level barriers are an example of public-stigma perpetuating a cycle of self-stigma that Vogel et al. (2013) discusses within the context of mental illness and in turn, a diagnosis of dementia.

**Dementia-Related Stigma.** One way in which dementia has been characterized in a negative light is related to behavioral changes and the changes to the subjective inner self that occur over the course of the disease (Kessler et al., 2012). These changes threaten a person's sense of reality about themselves and their environment. With their sense of reality threatened, subsequent internalized stigma can interfere with their seeking help because they may be afraid of others seeing that change for themselves (Cheng et al., 2011). The behavioral changes associated with dementia can lead to perceptions of people with dementia as dangerous; as a result, people often create distance from people with dementia by socially distancing themselves or avoiding them during daily activities (Nguyen & Li, 2020). Other symptoms of dementia, such as poor self-care and incontinence in community and care settings may cause negative attitudes and alarmist opinions from other lay people or even from professionals meant to administer care (Graham et al., 2003).

It is not unheard of for people to refer to those they know with the disease in past-tense and with terms not unlike 'the living dead' (Behuniak, 2011; Corner & Bond, 2004). Corner and

Bond (2004) demonstrated as such in an in-depth qualitative study where they interviewed cognitively intact older individuals about their perceptions of developing dementia, including questions about people they knew with some form of dementia. Despite these individuals still being alive, the participants showed examples of this past-tense referral about people they knew with a form of dementia, coupled with their own internalized stigma of dread towards the disease.

How individuals and societies view dementia, however, may largely depend on culture. Aspects like acculturation and family-centered cultural values are two areas that may predict how different cultures form their beliefs and knowledge about dementia as a broad concept (Sayegh & Knight, 2013). In Eastern and more collectivistic cultures, society broadly tends to view dementia as a more natural part of aging, a part that is taken in stride as the younger generation begins to take care of their parents as per their social custom (Cipriani & Borin, 2015). Within traditional Chinese and Indian cultures, family exists at a fundamental level, often with the older parents naturally going to live with their children as they grow older; whatever comes may be seen as natural or even as retribution for past deeds in some instances (Cipriani & Borin, 2015). This view of a family model may help to insulate people with dementia from potentially stigmatic beliefs.

In Western and individualistic cultures, many people broadly see dementia as an abnormal process of aging that impairs cognition, one that many see as terrifying (Cipriani & Borin, 2015). However, even in Western cultures, there are differences among minority groups, and differences in family values may help to predict and influence the importance and social benefit of seeking care (Sayegh & Knight, 2013). Native Americans have been observed to view dementia as being both a normal part of aging as well as a transition into the next world, a

transition in which elders can communicate with the other side through the hallucinations that may sometimes accompany different forms of dementia (Henderson & Henderson, 2002). Black Americans have been observed to treat dementia as a lesser subjective threat than White Americans and have been shown to take more of a spiritual approach to diagnosis and caregiving, sometimes being less likely to turn to modern medicines to slow cognitive decline (Connell et al., 2009). Each culture though comes with its own sets of negative, stigmatizing beliefs, regardless of how family-oriented they may or may not be in the treatment towards dementia.

While research broadly shows that different cultures treat a diagnosis involving dementia differently, it also shows similar findings with how each culture approaches the stigma surrounding dementia. Some of the previously discussed behaviors that can lead to individuals with dementia socially isolating and existing as a person referred to in the past-tense are still seen in more collectivistic cultures. For example, individuals in Muslim cultures may hide a dementia diagnosis from friends and even withdraw from the person with the disease due to fear of mockery or criticism from peers (Cipriani & Borin, 2015). Japanese cultures may interpret a person with dementia as being physically alive but socially dead (Henderson & Traphagan, 2005). Similarly, Korean and Chinese Americans may view dementia as a form of insanity or “craziness,” born from a failure to remain active throughout one’s life (Lee et al., 2010; Zhan, 2004). Other qualitative studies have found that Black African and Caribbean communities present in the United Kingdom have been known to view dementia as a “white person’s illness” (Nguyen & Li, 2020).

The stigma surrounding dementia appears to have negative consequences even in the diagnosis stage. Avoiding a diagnosis due to fear might paradoxically lead to the severe

behaviors people discriminate against. For example, multiethnic groups of both individualistic and collectivistic cultures residing in the United States appear to exhibit a significantly more advanced stage of the disease when initially seeking medical help than non-Hispanic White Americans do (Sayegh & Knight, 2013). This may be due to the protective factors of family-centered cultural values that prevent them from engaging in timely evaluations. This may also be due to people in minority cultures tending to attribute cognitive changes to normal aging, only reaching out to seek help when their loved ones begin to exhibit the more stigmatizing behaviors of combativeness, anger, wandering, and hallucinations (Hughes et al., 2009). This can further perpetuate the idea of dementia being associated with dangerous and alarming behavior.

**Ageism and Age-based Stereotypes.** As previously stated, stigma towards individuals with dementia is not uniform, even in cultures that tend to act a particular way towards it. In addition, dementia stigma can be intertwined with the Ageism commonly directed towards older individuals. Ageism is defined by Butler (1995) as, “a process of systematic stereotyping and discrimination against people because they are old” (as cited in Bodner, 2009, p. 1003). Stereotypes about older adults develop starting in childhood, when children begin to hear negative things about aging (Bennett & Gaines, 2010). Some of the more negative and notable stereotypes concern the ideas that older people are more dependent, incompetent, and senile (Coudin & Alexopoulos, 2010). Like most external factors that get internalized, these negative stereotypes are often the ones that have the most adverse outcome on older people’s senses of social and self-identity, unintentionally contributing to negative perceptions of themselves (Levy, 2009). On the other hand, positive aging stereotypes people may experience include ideas that older people have more wisdom, are more accomplished, and are more insightful.

Ageism may moderate stigmatizing attitudes about dementia in some cases. For example,

Werner et al. (2020) examined public-stigma towards both younger and older individuals with dementia, and found that older individuals were overall treated with less stigma, likely due to the preexisting paternalistic stereotypes the general public projects onto older people already. Older individuals are typically expected to have difficulties in certain areas, so they are not treated as harshly, whereas a younger individual who may be experiencing an earlier onset disease or exhibiting behavioral changes that may be perceived as being “different” will be treated as such.

Conversely, the self-stigma that comes from dementia may be compounded by the fact that stereotypical reminders of actual age make it harder for older individuals to distance themselves from normative memory decline (Hummert, 2011). Memory complaints may be subjective in nature, but they can be exacerbated by the active memory monitoring that comes from the knowledge that memory declines are associated with chronological age. Individuals who may be aware that they are experiencing cognitive changes also may be more prone to perceiving the surrounding stigma associated with dementia throughout society (Fowler et al., 2012).

Age-related stereotypes about cognitive function can also impact actual cognitive performance, as illustrated by the research on Stereotype Threat. For example, in one recent study, Bouazzaoui et al. (2016) found that individuals who were threatened with age-related stereotypes tended to perform worse on an episodic memory task. The stress and worry related to the aging stereotypes and the stigma surrounding them may then negatively impact an individual’s worry for developing the disease and confirming those stereotypes, thereby enhancing it (Bouazzaoui et al., 2016).

**Anticipated Stigma and Dementia Worry.** Because dementia worry typically occurs in response to a future threat rather than a current health problem, it may be particularly linked to

anticipated stigma, or the internalization of feelings of expecting to experience prejudice, discrimination, and stereotyping from others in the future (Earnshaw & Chaudoir, 2009). A relationship between worry and anticipated stigma was demonstrated in Maxfield and Greenberg's (2021) study with middle-aged and older individuals. They assessed participants' perceptions for a hypothetical scenario where they developed dementia, and measured participants' subsequent levels of anticipated stigma from friends and family to investigate how this affected their dementia worry. Consistent with the domains of the construct of dementia worry and the role that identity plays in it, Maxfield and Greenberg found that increased anticipated stigma from friends and family was in fact associated with increased dementia worry among participants.

### **The Stereotype Content Model**

One limitation of prior research on both dementia worry and dementia stigma has been a lack of a single guiding theoretical perspective for integrating the research. While there are a number of possible approaches that may be applied to this topic (such as the Health Beliefs Model; Janz & Becker, 1984), the focus of the current study is on how stereotypes associated with dementia and aging can influence the relationship between anticipated stigma and dementia worry.

The stereotype content model (SCM) developed by Fiske et al. (1999) describes a framework that "predicts how groups are 'sorted' in a given society, and how a group's position in this assortment relates to the types of prejudice its members might suffer" (p. 268). This model posits that two facets determine how individuals are subsequently sorted: through their status in society and through their interdependence. Typically, status will predict assessments of competence, whereas interdependence will be an indicator of perceived warmth. These two

facets of the SCM produces four different types of groups: competent and warm, competent and cold, incompetent and warm, and incompetent and cold (Cuddy et al., 2005). However, the SCM suggests that stereotyped groups tend to have mixed positive and negative content (i.e. competent and cold; incompetent and warm). Groups perceived as competent often lack warmth (e.g., people who are wealthy), whereas those seen as incompetent typically receive warmth based on the flawed assumption that status invariably derives from the ability of the individual in question (e.g., people who are disabled).

Typically, these stereotypes serve as a way to elevate the 'in-group' and make them more comfortable in society by denigrating whom they perceive to be the 'out-group' (Cuddy et al., 2005). Often, referring to people in the out-group will reinforce the stigma itself, and perpetuate the self-isolation and social exclusion that can happen as a result of the internalization of that public-stigma (Benbow & Jolley, 2012). In-group factions of society tend to be wealthier people with power, whereas out-group individuals tend to be those who are poorer and are minoritized in various social groups. It is very rare for a group to be perceived as both competent and warm, and as such, typically one's own group is the only one to garner that special combination (Fiske et al., 1999). Despite one's own group being assigned to both positive conditions, it is also rare for any one group of people to be subjected to both negative conditions due to reasons as determined by the in-group.

The SCM provides a framework to view the oscillating nature of positive and negative stereotypes that older individuals generally garner. Older adults tend to be stereotypically viewed as incompetent but warm. The warmth component serves as a positive indicator, whereas the incompetent component serves as the negative facet, further reinforcing the mixed model approach (Fiske et al., 1999). In addition, the warm/incompetent stereotype has been found to

apply specifically to people with dementia. In a study of American students, O'Connor and McFadden (2012) found that older adults who suffered from dementia were indeed categorized as warmer than older adults with no known health issues.

The warm/incompetent stereotype is often seen cross-culturally because of the perceived social position of elderly individuals. In Eastern cultures such as China and Japan, older individuals' place in society is woven into the fabric of their culture; at a certain age, a person's children will take their parents into their homes and begin to care for them much as they had been when they were children (Cipriani & Borin, 2015). In many ways, this is a normal part of the life process and serves as a reinforcer for the 'incompetent' facet of the SCM. Because of this, when elderly people behave consistently with the incompetent stereotype, they are viewed more favorably on the warmth part of the stereotype and face less stigma (Cuddy et al., 2005). Stigma associated with dementia may therefore be viewed on a spectrum with extreme endpoints: "dangerousness" lies at one end, while being too sympathetic toward the concept of dementia, and individuals with it lie, at the other. Projecting the idea of helplessness and dependence onto individuals with dementia can do just as much harm as being too wary of them (Kane et al., 2020).

One reason older individuals may stereotypically be attributed with lower competence relative to warmth may be because previous researchers have found that competence-related traits were lost on average nine years earlier than warmth-related traits, lending the greater possibility for an older individual to be viewed as warm rather than competent (Cuddy et al., 2005). The warmth attributed to these individuals is typically viewed as friendliness and may even be due to the finding that older people, regardless of gender, are typically seen as more feminine than younger individuals (Kite et al., 1991). Older individuals are also expected to have



competence problems and memory failures (Erber & Prager, 1999). These memory failures within older individuals are, thus perceived to be due to intellectual incompetence rather than an inattentional effort often perceived to be the cause from younger individuals.

### **The Current Study**

The proposed study builds on prior research linking anticipated stigma and dementia worry by incorporating predictions based on the Stereotype Content Model. People aged 40-65 were recruited for this study via an online sample from Prolific. While taking part in the study, participants completed two questionnaires: the Dementia Worry Scale developed by Kinzer and Suhr (2016), which assesses aspects of Alzheimer's disease worry and thoughts about either developing or having dementia, along with the Chronic Illness Anticipated Stigma Scale (CIASS) developed by Earnshaw et al. (2013), which is typically used to explore stigma anticipated and experienced by people living with chronic illnesses. Importantly, unlike the prior measure used to measure anticipatory stigma related to dementia (Maxfield & Greenberg, 2021), the CIASS asks about anticipated stigma in three domains: work, healthcare, and friends and family.

My primary hypotheses were that (1) scores on the anticipated stigma measure will be higher in the work domain than in the friends and family domain, and (2) the relationship between anticipatory stigma and dementia worry should be stronger in the work domain than in the friends and family domain. This is because people with dementia are perceived to have low competency, which should produce greater threat appraisals in the work domain than in the healthcare professionals or friends and family domains. While the a priori status of healthcare stigma is less clear, I expected healthcare to fall between the other two domains in these analyses. Finally, as exploratory analyses, I investigated whether these effects remained

significant after controlling for (1) having a first-degree relative with dementia, (2) scores on a general measure of anxiety, and (3) subjective memory beliefs.

### **Method**

The current study was determined to be exempt by the Appalachian State University's Institutional Review Board, and was pre-registered through the Open Science Framework (OSF; <https://osf.io/6dskb>). A copy of the exemption letter is included in Appendix A. In line with Simmons et al.'s (2011) recommendations, with this current study, we report how we determined our sample size, all data exclusions, and all measures in the study.

### **Design**

The design is a within-subjects, correlational design that looks at the relationships between anticipated stigma and dementia worry. Anticipated stigma served as the conceptual independent variable with the responses participants offer across the three domains in response to the Chronic Illness Anticipated Stigma Scale (CIASS) serving as the way to operationalize it. The dependent variable is scores on the dementia worry scale to obtain a measure of dementia worry.

### **Participants**

Participants were recruited via an online sample gathered from Prolific with the geographic region set to the United States to control for geographic and cultural differences. The study was described as a study of "attitudes about health conditions," rather than about dementia specifically, to reduce possible demand characteristics. Prior to participation, all participants indicated they gave consent; following the completion of the study, participants were awarded \$3.19 as compensation for their time.

An a priori power analysis was conducted to determine the minimum number of participants needed to detect significant effects. The minimum number of participants was determined to be 122, the number needed to detect a significant difference between scores on the work and friends and family domains on the CIASS with power of .95 for a small effect (reference point by Maxfield & Greenberg, 2021 and Earnshaw et al., 2013). The maximum number of participants was determined to be 452, the number needed to detect a significant change in R-squared in a hierarchical regression predicting dementia worry from family stigma (Step 1) and work stigma (Step 2). As described in the preregistration, the exact number of participants was driven by funding availability.

For the current study, 438 participants were recruited with the intent to have the sample be evenly distributed across age and sex. One of the pre-established inclusion criteria was that participants still be working for pay; six participants, however, indicated that they were not currently working. We, therefore, excluded these participants from the analyses, leaving us with 432 eligible participants. Of these 432 participants, 219 participants were women, and 213 were men. The mean age of participants was 51.2 years ( $SD = 7.18$ ); the minimum age of participants was 40 and the maximum age was 65. Participants were evenly distributed across age bands of 40-49 ( $n = 184$ ), 50-59 ( $n = 180$ ), and 60-65 ( $n = 72$ ) and highly educated with a mean of 16.5 years of formal education ( $SD = 2.99$ ).

Demographic characteristics were also collected for participants, including racial/ethnic identity and religious denomination. The sample was predominantly Christian ( $n = 237$ ; 54.9%), with participants who identified as Atheist ( $n = 75$ ; 17.4%) and Agnostic ( $n = 69$ ; 16.0%) as the closest successors. The sample was also predominately White ( $n = 390$ ; 90.3%), with participants

who identified as Black or African American ( $n = 22$ ; 5.1%) and Asian ( $n = 17$ ; 3.9%) as the closest successors.

## **Measures**

### ***Demographic Information***

Previous research on dementia worry and the surrounding anxiety that accompanies it has taken education and exposure into account when assessing the degree to which people experience the worry (Cutler & Hodgson, 2001; Cutler, 2015; Corner & Bond, 2004). To account for these potential effects, participants were asked their level of education and if they had any first-degree relatives who have had or currently have a formal dementia diagnosis. This latter question was embedded within other common chronic diseases so as to not draw the participants' attention to the purpose of the study (see Appendix C). Given the differences in culture and differing degrees of stigma surrounding dementia, participants were also asked to report their race, ethnicity, and religious affiliation (items included relate to religion, denomination, and if they identify as Evangelical). Due to some individuals experiencing prolonged neurological symptoms from COVID-19 (National Institute of Health, 2021), participants were asked if they have been diagnosed with COVID-19, the severity of it, and if they consider themselves a "long hauler." Finally, participants were also asked if they were still actively involved in the workforce.

### ***Depression, Anxiety, Stress Scale***

Because Dementia worry may overlap with health anxiety (Kessler et al., 2012), participants completed the Depression, Anxiety, and Stress Scale (DASS) (Lovibond & Lovibond, 1995). The DASS was used to control for already present anxiety some people may exhibit. Generally, the DASS is a measure that is used to assess and distinguish between anxiety

and depression, as well as between symptoms of physical arousal and generalized anxiety. The scale is composed of 21 items measured on a 4-point Likert scale ranging from 0 = “Did not apply to me at all” to 3 = “Applied to me very much, or most of the time.” An example item from the measure includes, “I was intolerant of anything that kept me from getting on with what I was doing.”

The scale loads onto three factors: depression, anxiety, and stress-related items, and demonstrates reliable to excellent validity (Depression,  $\alpha = .94$ ; Anxiety,  $\alpha = .87$ ; and Stress,  $\alpha = .91$ ). For the current study, the reliabilities for each of the subscales was calculated and demonstrated similar values (Depression,  $\alpha = .93$ ; Anxiety,  $\alpha = .82$ ; and Stress,  $\alpha = .89$ ). To calculate totals for each subscale, scores are averaged. Greater scores indicate higher levels of depression, anxiety, and stress. The copy of the DASS being used for this study can be found in Appendix D.

### ***Chronic Illness Anticipated Stigma Scale***

Earnshaw et al. (2013) originally developed the Chronic Illness Anticipatory Stigma Scale (CIASS) to measure stigma among groups of people living with chronic illnesses across the three domains of friends and family members, work colleagues, and healthcare providers. The scale is composed of 12 items measured on a 5-point Likert scale ranging from 1 = “very unlikely” to 5 = “very likely.” The scale includes three subscales oriented towards anticipated attitudes one might receive from friends and family, work colleagues, and healthcare workers. To calculate a measure of anticipated stigma from each subscale, scores are averaged. Greater scores indicate higher levels of anticipated stigma from friends and family, work colleagues, and healthcare workers. Earnshaw et al.’s analysis of factor loadings on the scale determined an

internal consistency of .95; the friends and family, work colleagues, and healthcare workers subscales likewise produced alpha levels of .92, .95, and .95 respectively.

Because one of the hypotheses of the current study involved comparing stigma in the different domains, the items of these scales were put in random order to avoid testing effects. This did not greatly impact the reliabilities for each of the subscales in the current study were slightly lower but still strong (friends and family,  $\alpha = .89$ ; work colleagues,  $\alpha = .90$ ; and healthcare workers  $\alpha = .85$ ). A copy of the CIASS instructing participants to focus on having dementia can be found in Appendix E.

### ***General Health***

The MOS 36-item Short Form Survey (Ware & Sherbourne, 1992) looks at nine subscales to assess an index of an individual's perceived general health. The inclusion of this scale serves to give a general idea of how participants rate their own overall health. The scale is composed of 36 total items. The 'physical functioning' subscale comprises 10 items ( $\alpha = .93$ ; observed  $\alpha = .94$ ); the 'role functioning/physical' subscale comprises 4 items ( $\alpha = .84$ ; observed  $\alpha = .89$ ); the 'role functioning/emotional' subscale comprises 3 items ( $\alpha = .83$ ; observed  $\alpha = .86$ ); the 'energy/fatigue' subscale comprises 4 items ( $\alpha = .86$ ; observed  $\alpha = .89$ ); the 'emotional well-being' subscale comprises 5 items ( $\alpha = .90$ ; observed  $\alpha = .85$ ); the 'social functioning' subscale comprises 2 items ( $\alpha = .85$ ; observed  $\alpha = .83$ ); the 'pain' subscale comprises 2 items ( $\alpha = .78$ ; observed  $\alpha = .89$ ); the 'general health' subscale comprises 5 items ( $\alpha = .78$ ; observed  $\alpha = .85$ ); the 'health change' subscale is one question. A copy of the total scale can be found in Appendix F.

### ***Dementia Worry Scale***

Many previous studies investigating dementia worry have used a single question to attempt to measure participants' perceptions of dementia. Before Suhr and Isgrigg's (2011) development of a 15-item Dementia Worry Scale, researchers typically assessed worry with the question of "How much do you worry that you will develop Alzheimer's Disease (Werner et al., 2020)?" Kinzer and Suhr's (2016) version of the Dementia Worry Scale parses the scale from 15 to 12 items to assess the dismissability and controllability of thoughts about both developing and having dementia.

The 12-item version of this scale is used in this study; it is comprised of a 5-point Likert scale ranging from 1 = "not at all typical of me" to 5 = "very typical of me" with higher averaged scores indicating higher levels of dementia worry. An example item from the scale is "When I can't remember something, I find myself wondering whether I have dementia." Kinzer and Suhr's analysis of factor loadings on the scale determined an internal consistency of .91. For the current study, the reliability of the scale was calculated and found to be consistent with prior assessments ( $\alpha = .94$ ). A copy of the Dementia Worry Scale used can be found in Appendix G.

### ***Memory Controllability Inventory***

Because subjective memory may play a role in an individual's concern over developing dementia, an index of one's subjective memory was taken with the Memory Controllability Inventory (MCI; Lachman et al., 1995). The MCI is a 19-item scale measured on a 7-point Likert scale with choices ranging from 1 = "Strongly disagree" to 7 = "Strongly agree." An example item from this scale includes, "I can't seem to figure out what to do to help me remember things." The scale is broken into six subscales of Present Ability ( $\alpha = .58-.78$ ), Potential Improvement ( $\alpha = .62-.75$ ), Effort Utility ( $\alpha = .65-.73$ ), Inevitable Decrement ( $\alpha = .58-.77$ ),

Independence ( $\alpha = .49-.68$ ), and Alzheimer's Likelihood ( $\alpha = .65-.73$ ). To determine levels of concern and endorsement over aging and memory controllability, scores for each subscale are averaged. Higher scores indicate greater endorsement and concerns.

For the current study, we calculated the reliability for each subscale and found similar values for each (Present Ability,  $\alpha = .65$ .; Potential Improvement,  $\alpha = .66$ ; Effort Utility,  $\alpha = .81$ ; Inevitable Decrement,  $\alpha = .74$ ; Independence,  $\alpha = .68$ ; and Alzheimer's Likelihood,  $\alpha = .61$ ). To be consistent with prior research (Kinzer & Suhr, 2016), I primarily focused on the Present Ability and the Alzheimer's Likelihood subscales. The Present Ability subscale assesses a participant's degree of confidence in their own memory functioning, an important consideration with worry over developing dementia. The Alzheimer's Likelihood subscale assesses participants' perceived likelihood of developing dementia. Previous research by Kinzer and Suhr (2016) have demonstrated support for the association between both subscales and dementia worry. A copy of the MCI can be found in Appendix H.

### ***SCM Framework Scale***

To ensure that participants believed that people with dementia are perceived with high warmth and low competence, the competence and warmth scale developed by Fiske et al. (2002) was used. The scale overall is a 15-item scale measured on a 5-point Likert scale with choices ranging from 1 = "Not at all" to 5 = "Extremely." Participants were administered four versions of this scale and asked to think about how people with dementia, migrant workers, welfare recipients, and wealthy individuals are viewed by American society. In Fiske et al.'s (2002) original study, each of these groups was seen to belong to separate clusters of warmth vs. competence, justifying their inclusion in the present study.



To determine levels of competence, warmth, status, and competition, scores for each subscale are averaged. The scale is separated into four subscales of Perceived Competence ( $\alpha = .85$ ) Perceived Warmth ( $\alpha = .82$ ), Status ( $\alpha = .78$ ), and Competition ( $\alpha = .61$ ). Higher scores indicate greater endorsement of the belief that this group of people are perceived a certain way in American society. Because we are primarily interested in warmth versus competence, these were the two subscales used here. Reliabilities of these measures for the current study ranged from  $\alpha = .86$ -.91 for Competence and  $\alpha = .88$ -.90 for Warmth. A copy of the questions can be found in Appendix I.

### **Procedure**

Before the study began, participants indicated their consent, acknowledging their participation in the study with the acknowledgment that they may opt-out of the study at any point. A copy of the consent form can be found in Appendix B. Participants then filled out the demographics' questionnaire. Following demographics, participants were administered the DASS-21 to evaluate their perceptions of their levels of depression, anxiety, and stress. Then, participants completed the CIASS questionnaire to evaluate their beliefs on potential anticipated stigma towards themselves from friends and family, work colleagues, and healthcare workers should they be diagnosed with a form of dementia. Between the CIASS questionnaire and the dementia worry scale, participants filled out the SF-36. Following the dementia worry scale, participants were administered the MCI to assess for a subjective assessment on their current memory status. Finally, participants were administered the SCM Framework questionnaire to ensure that participants reinforced the mixed stereotype of people with dementia being viewed as warm but incompetent. The true nature of the questionnaires was not revealed to the participants. Once the study concluded, each participant was compensated for their time.

## **Analysis Strategy**

As described previously, my two main hypotheses were that (1) scores on the anticipated stigma measure will be higher in the work domain than in the friends and family domain, and (2) the relationship between anticipatory stigma and dementia worry should be stronger in the work domain than in the friends and family domain. The hypothesis that scores on the CIASS should be greater for work-based than friends and family-based stigma, was tested using a pairwise samples t-test. This t-test compared the average levels of work-based anticipated stigma to friends and family-based stigma. The hypothesis that the relationship between stigma and dementia worry should be higher in the work domain than the friends and family domain was tested using a hierarchical multiple regression model with dementia worry as the dependent variable. The scores for friends and family-based stigma were entered in step 1, and the scores for work-based stigma were entered in step 2. Change in R-squared was evaluated to determine if work-based stigma predicted dementia worry above and beyond family-based stigma. We chose this analysis strategy based in part on the practicality of obtaining enough participants to detect statistically significant effects: the number needed to detect a change in R-squared was significantly lower than the number required to detect a difference in the bivariate correlations.

Finally, additional exploratory analyses were conducted to determine if the above effects remained after controlling for other theoretically relevant predictors (1st order family member with dementia, general anxiety, or subjective memory). For this covariate analysis, the three predictors (family history, general anxiety, and subjective memory measures) were entered at Step 1, friends and family stigma was entered at Step 2, and work stigma was entered at Step 3. The change in R-Squared was evaluated at each step.

## Results

### Assumption Check

#### *Anticipated Stigma and Stereotype Content*

To ensure that participants were thinking about people with dementia with the same amount of warmth versus competence as Fiske et al.'s (1999) original study, a 2 (Domain: Warmth and Competence) x 4 (Group: Dementia, Welfare, Rich, Migrant Workers) Repeated Measures ANOVA was conducted on the SCM Framework scores.

As may be seen in Figure 1, the interaction between the Domain and Group was statistically significant,  $F(3, 1293) = 1187.08, p < .001, \eta_p^2 = .734$ . In line with the previous research, participants rated people with dementia as being higher in Warmth ( $M = 2.70, SE = .039$ ) than in Competence ( $M = 1.65, SE = .029$ ), while Rich people were viewed as lower in Warmth ( $M = 2.40, SE = .040$ ) than in Competence ( $M = 4.36, SE = .033$ ).

A Bonferroni correction was applied for post-hoc comparisons within the interaction to examine where any significant differences could be found. Within each of the groups, the differences between both warmth and competence were significant (all  $p < .001$ ). Within the Warmth domain, the differences between all the groups were significant. The difference between the Welfare and Rich group was significant at  $p = .046$ , while the difference between the Welfare and Dementia group was significant at  $p = .001$ . The differences between the rest of the groups within the Warmth domain were all significant at  $p < .001$ . Within the competence domain, the difference between each of the groups was also significant (all  $p < .001$ ).

Most importantly for the current study, the Dementia group had lower ratings of competence than any other group and had higher levels of warmth than either welfare recipients or rich people.

## Confirmatory Analyses

### *Domain Differences in Anticipated Stigma*

To determine whether participants anticipated greater levels of stigma from work colleagues than friends and family, a paired-samples t-test was conducted, comparing participants responses on each of the CIASS subscales of anticipated stigma from friends and family and anticipated stigma from work colleagues. Results showed that participants had greater levels of anticipated stigma from their work colleagues ( $M = 3.69$ ,  $SD = 1.11$ ) than from their friends and family ( $M = 2.08$ ,  $SD = 1.05$ ),  $t(359) = -30.5$ ,  $p < .001$ ,  $d = -1.47$ , 95% CI: [-1.60, -1.33], consistent with my hypothesis.

I also examined how much anticipated stigma participants expected to feel from healthcare workers, and where in relation those feelings were compared to anticipated stigma from work colleagues and friends and family. A Repeated Measures One-Way Analysis of Variance (ANOVA) was conducted, comparing participants responses on each of the CIASS subscales of anticipated stigma from friends and family, anticipated stigma from work colleagues, and anticipated stigma from healthcare workers. Results showed that there was a significant difference between all three domains,  $F(2, 862) = 655$ ,  $p < .001$ ,  $\eta_p^2 = .603$ . To determine which conditions were different from each other, a Bonferroni-corrected post hoc test was conducted. Levels of anticipated stigma from friends and family ( $M = 2.08$ ,  $SD = 1.05$ ) were significantly less than those of both anticipated stigma from work colleagues ( $M = 3.69$ ,  $SD = 1.11$ ) and healthcare workers ( $M = 2.37$ ,  $SD = 0.96$ ). Levels of anticipated stigma from healthcare workers was also significantly less than levels of anticipated stigma from work colleagues, all  $p < .001$ . These results suggest that participants felt greater levels of potential

anticipated stigma from colleagues at work than what they might experience from their friends and family, and even from healthcare workers, consistent with my hypotheses.

### ***Relationship between Anticipated Stigma and Dementia Worry***

Prior to any further analyses, bivariate correlations were conducted between dementia worry scores and each of the variables of interest (education, age, family history, generalized anxiety, present ability, Alzheimer's likelihood, anticipated stigma from friends and family, anticipated stigma from work colleagues, warmth attitudes towards people with dementia, and competence attitudes towards people with dementia). A complete report of the correlations conducted can be found in Table 1. Most importantly for my hypotheses, the bivariate correlation between dementia worry and anticipated stigma from friends and family yielded a moderate positive relationship, indicating that participants who indicated that they expected to feel more stigma from friends and family would have increased levels of dementia worry. The bivariate correlation between dementia worry scores and anticipated stigma from work colleagues also yielded a moderate positive relationship, indicating that participants who indicated that they expected to feel more stigma from work colleagues also reported increased levels of dementia worry. It should be noted, however, that the relationship between stigma and dementia worry was not stronger for the work domain than for the friends and family domain, contrary to my hypothesis.

Despite the fact that the relative size of the correlations was not as I predicted, I still ran the planned hierarchical multiple regression analysis to determine whether anticipated stigma from work colleagues predicted elevated levels of dementia worry above and beyond anticipated stigma from friends and family. That is, this analysis determines whether work stigma contributes any *unique* variance to the prediction of dementia worry. The results of this analysis

can be found in Table 2. In Step 1 of the regression model, anticipated stigma from friends and family was entered, which explained 8.46% of the variance in dementia worry. With the inclusion of anticipated stigma from work colleagues entered in Step 2, the total variance explained by the model increased to 9.62%,  $F(2,429) = 22.8, p < .001$ . The second step of this regression model with anticipated stigma from work colleagues, significantly predicted increased levels of dementia worry among participants (standardized beta = .12,  $p = .020$ ). The  $\Delta R^2$  of .01 produced from Step 1 to Step 2 was significant as well,  $F(1,429) = 5.47, p = .020$ . The results of this regression model provide support for the hypothesis that anticipated stigma from work colleagues would predict dementia worry above and beyond that of anticipated stigma from friends and family.

## **Exploratory Analyses**

### ***Covariate Analysis***

Following confirmatory analyses that aimed to provide evidence for the main hypotheses, a hierarchical multiple regression model was used to examine whether the hypothesized relationships held when other variables were controlled. As mentioned prior, bivariate correlations were conducted between dementia worry scores and each of the variables of interest (family history, generalized anxiety, present ability, Alzheimer's likelihood, warmth attitudes towards people with dementia, and competence attitudes towards people with dementia). A complete report of the correlations conducted can be found in Table 1.

Of the variables being used in the covariate analysis, family history yielded a weak positive correlation with dementia worry, showing that having a positive family history of dementia led to increased worry of developing dementia. Generalized anxiety measured through the DASS was also moderately positively correlated with dementia worry, indicating greater

levels of anxiety was associated with greater levels of dementia worry. Likewise, Alzheimer's likelihood yielded a strong positive correlation with dementia worry, indicating the higher concern a participant had about their likelihood of developing Alzheimer's disease, the more dementia worry they endorsed. Unlike the previous bivariate correlations, the correlation between present ability and dementia worry yielded a moderate negative correlation. This negative relationship indicated that the more confident participants were in their current ability to function, the less dementia worry they endorsed having.

Like the previous regression model, this exploratory model analyzed whether anticipated stigma from work colleagues predicted elevated levels of dementia worry above and beyond anticipated stigma from friends and family with the added covariates of (1) family history of dementia, (2) subjective memory complaints using the subscales Alzheimer's Likelihood and Present Ability, and (3) generalized anxiety. The complete results of this analysis may be found in Table 3.

In Step 1 of the regression model, generalized anxiety captured through the DASS (standardized beta = .15,  $p < .001$ ), family history of having dementia (standardized beta = .21,  $p = .037$ ), the Alzheimer's likelihood subscale (standardized beta = .59,  $p < .001$ ), and the Present Ability subscale from the MCI scale (standardized beta = -.06,  $p = .157$ ) were entered to serve as covariates; together, these variables explained 46.7% of the variance in dementia worry and produced a significant model,  $F(4,427) = 93.4, p < .001$ . With the inclusion of anticipated stigma from friends and family (standardized beta = .08,  $p = .026$ ) entered in Step 2, the total variance in dementia worry that was explained increased to 47.3%, producing a significant model,  $F(5,426) = 76.4, p < .001$ . With the inclusion of anticipated stigma from work colleagues (standardized

beta = .05,  $p = .205$ ) entered in Step 3, the total variance explained by the model increased further to 47.5%, producing a significant model,  $F(6,425) = 64.0, p < .001$ .

From Step 1 to Step 2, an additional 0.61% of the variance was able to be explained, producing a significant change,  $F(1,426) = 4.96, p = .026$ . From Step 2 to Step 3, an additional 0.20% of the variance was able to be explained, producing a nonsignificant change,  $F(1,425) = 1.61, p = .205$ . After accounting for possible other factors, anticipated stigma from work colleagues did not significantly predict increased levels of dementia worry among participants above and beyond anticipated stigma from friends and family.

It should be noted that including the Alzheimer's likelihood subscale in the regression accounted for a substantial portion of the variability in dementia worry, with a standardized beta of .56 in the full model. This suggests substantial overlap between these two measures. Running the above analyses without the Alzheimer's Likelihood measure yields work stigma as a significant predictor (standardized beta = .12,  $p = .011$ ), and can be found below.

In Step 1 of this regression model, generalized anxiety captured through the DASS (standardized beta = .23,  $p < .001$ ), family history of having dementia (standardized beta = .36,  $p = .004$ ), and the Present Ability subscale from the MCI scale (standardized beta = -.30,  $p < .001$ ) were entered to serve as covariates; together, these variables explained 20.2% of the variance in dementia worry and produced a significant model,  $F(3,428) = 36.1, p < .001$ . With the inclusion of anticipated stigma from friends and family (standardized beta = .19,  $p < .001$ ) entered in Step 2, the total variance in dementia worry that was explained increased to 23.5%, producing a significant model,  $F(4,427) = 32.8, p < .001$ . With the inclusion of anticipated stigma from work colleagues (standardized beta = .12,  $p = .011$ ) entered in Step 3, the total variance explained by the model increased further to 47.5%, producing a significant model,  $F(5,426) = 27.9, p < .001$ .



From Step 1 to Step 2, an additional 3.29% of the variance was able to be explained, producing a significant change,  $F(1,427) = 18.36, p < .001$ . From Step 2 to Step 3, an additional 1.15% of the variance was able to be explained, producing a significant change,  $F(1,426) = 6.48, p = .011$ . A further breakdown of all regression coefficients from this model can be found in Table 4.

### ***Relationship between Dementia Worry and SCM scores***

Finally, to help understand the regression results, I also examined bivariate correlations between dementia worry, stigma, and stereotype content (see Table 1). The bivariate correlation between dementia worry and warmth attitudes towards people with dementia did not produce a relationship, though dementia worry did yield a weak negative correlation with competence attitudes towards people with dementia. This negative relationship indicates that the less competent participants viewed people with dementia as being, the more dementia worry they endorsed having. Bivariate correlations between competence attitudes and each of the anticipated stigma domains of work colleagues and friends and family also yielded weak to moderate, negative relationships. The correlation between competence attitudes and stigma from work colleagues was stronger than with stigma from friends and family, though both still showed that the less competent participants viewed people with dementia as being, the more anticipated stigma they expected from both groups. Finally, bivariate correlations between warmth attitudes and each of the anticipated stigma domains of work colleagues and friends and family also yielded weak to moderate, negative relationships. Unlike with competence attitudes, the correlation between warmth attitudes and work colleagues was weaker than with friends and family, though again, both still showed that the warmer participants viewed people with dementia as being, the less anticipated stigma they expected from both groups.

## Discussion

The current study builds on prior research linking anticipated stigma and dementia worry by incorporating predictions based on the Stereotype Content Model (SCM). Consistent with the SCM, participants did endorse the stereotype that people with dementia were lower in competence than warmth, and lower in competence than other stereotyped groups. The two main hypotheses predicted that scores on the anticipated stigma measure would be higher in the work domain than in the friends and family domain, and that the relationship between anticipatory stigma and dementia worry should be stronger in the work domain than in the friends and family domain.

The first hypothesis was clearly supported: middle-aged participants who were still working for pay, expected significantly more stigma from work colleagues than friends and family if they were to receive a dementia diagnosis. The second hypothesis was partially supported: although the size of the relationship between stigma and worry was similar in both domains, stigma in the work domain did predict unique variance in dementia worry above and beyond the anticipated stigma from friends and family. When the covariates of family history, general anxiety, and subjective memory were included, stigma from friends and family remained a significant predictor, but the contribution from work stigma was no longer a unique predictor.

Overall, these results are consistent with those of Maxfield and Greenberg (2021), in that anticipated stigma from friends and family members was a significant predictor of dementia worry even after accounting for other factors (general anxiety, family history, and subjective memory). Anticipated stigma from coworkers however, did not contribute any unique variance to dementia worry when these covariates were included. This may be in part because of the substantial overlap between Alzheimer's Likelihood subscale of the MCI and the dementia worry

measure. The correlation between the Alzheimer's Likelihood subscale and the Dementia Worry scale used in this study is very strong. In addition, when the Alzheimer's Likelihood scale is included as a predictor of dementia worry, the model explains nearly half of the total variance before accounting for any of the anticipated stigma domains, and dwarfs even the contribution of general anxiety and family history. Taking out the Alzheimer's Likelihood scale as a predictor reduces explained variance to around a quarter of the total variance explained, and work stigma again becomes a unique predictor.

Given the substantial overlap between Alzheimer's Likelihood and Dementia Worry, it is important to distinguish between the constructs as they are being measured and what they can be used for. The Alzheimer's Likelihood subscale focuses more on the participants' perceived threat of developing Alzheimer's disease due to changes in cognitive status incorporated into a broader scale directed at assessing subjective memory. The Dementia Worry Scale measures the affective response to the perceived threat of developing dementia, independent of chronological age and cognitive status (Kessler et al., 2012). The overlap in variance between the scales demonstrated in the covariate analysis of this study demonstrates that both scales are measuring similar constructs, but because the element of the perceived threat is part of dementia worry, that overlap may be expected. In fact, there is some similarity in the questions asked by the two scales. Specifically, one of the items on the Alzheimer's Likelihood scale is "When I forget something, I am apt to think I have Alzheimer's Disease," which is nearly identical to item 3 on the Dementia Worry Scale, "When I can't remember something, I find myself wondering whether I have dementia." Because the Dementia Worry Scale is a more well-rounded measure of concerns about developing dementia, and shows much better reliability than the Alzheimer's Likelihood

scale of the MCI, the Dementia Worry Scale is important to have and consider its own entity capable of assessing people's concerns over developing dementia.

The results are also generally consistent with the SCM, in that people with dementia were viewed as having higher warmth than competence. The findings about the relationship between anticipated stigma and dementia worry were more complex than anticipated. Work stigma was not more strongly related to dementia worry than was stigma from friends and family, but it did predict unique variance in dementia worry. In other words, both types of stigma were contributors to dementia worry, but perhaps for different reasons. Looking at the correlations in Table 1, it may be noted that the "Competence" ratings for dementia patients on the SCM were related to dementia worry, but "Warmth" ratings were not. The less competent people with dementia were viewed as being, the more dementia worry participants endorsed having. Competence was also seen to be more strongly related to anticipated stigma from work colleagues than from friends and family, whereas warmth was more strongly related to anticipated stigma from friends and family than from work colleagues. Warmth may be higher for the friends and family domain because it is perceived as more important in the context of relationships with family and friends. These results further suggest that competence plays a key role in anticipated stigma from work colleagues. Perhaps being perceived as competent in a work environment is particularly important for one's livelihood, without which, they would have to rely on other means. This, in conjunction with threat appraisals produced for the work domain due to the stereotype that people with dementia are perceived to have low competency, were in fact, greater than those produced in the friends and family domain.

One other possible reason that anticipated stigma from work colleagues does predict dementia worry above and beyond anticipated stigma from friends and family may be due in part

to the pre-existing social norms that exist within family structures. The effects of these social norms are important in acknowledging that individuals still experience anticipated stigma from friends and family, as demonstrated by Maxfield and Greenberg (2021). For example, people may have different perceptions of receiving help from a spouse than from their children. Because spouses may be expected to help and be helped by one another (Thomas, 2010), people may not anticipate feeling stigma from a spouse. If an individual were to be helped by their children in older age, however, this might violate classical norms because the individual had previously cared for the child, thus reinforcing the perceived 'incompetent' stereotype of the SCM framework. Future research might investigate this question of competence viewed in traditional family structures in American culture with a combination of qualitative and quantitative measures, based around the full SCM scale that incorporates Status and Competition, as well as the Perceived Competence and Perceived Warmth subscales used in this study. While in different cultures, the social norms may be different and contribute to different results, qualitative interviews or even free-response questions within American culture could help to expand upon the negative connotations that surround younger family members helping older ones over someone their own age.

The results from this study further suggest that middle-aged individuals may exhibit some form of dementia worry even before they may be especially susceptible to a formal diagnosis. Family history, subjective memory, and generalized anxiety all provided evidence for predicting increased worry, along with potential stigma individuals might experience. Given the dimensions of the SCM and that these participants are still actively engaged in the workforce, these potential threat appraisals surrounding the idea of competence likely explains this relationship. As such, it is important to consider the kinds of education that is available to people of all ages, especially

this particularly susceptible middle-aged population. Benbow and Jolley (2012) outline several steps that may be helpful in informing potential educational programs that particularly address stigma and its role in perpetuating false and inaccurate information regarding dementia.

Education with exposure to people with dementia specifically would help to cut down on seeing people with dementia as being different and an isolated group.

By conducting more research and engaging with this population, we can ensure adequate steps be taken in regards to policy and management resources. The disability-inclusion model would pay particular attention to people with dementia (a disability, in this case) to make sure they are consulted and attended to on community matters (Benbow & Jolley, 2012). Continuing to treat people with dementia as different or of having needs that can be disregarded will only serve to reinforce certain aspects of stigma against dementia. An increase or persistence in general stigma towards dementia can only serve to create further worry in middle-aged adults due to the evident stigma they will be expecting to experience in the future.

### **Limitations & Future Directions**

Regardless of this study being conducted, limitations still exist. The present study uses an online sample of participants gathered through Prolific. This online sample is likely not representative of the true population of the United States. This sample was highly educated with participants having, on average, 16.5 years of formal education with limited variability. This may be part of the reason we did not find education to be a significant predictor of dementia worry.

An additional artifact of using Prolific was that we did not include a measure of objective memory performance like Kinzer and Suhr (2016) did with subscales from the Repeatable Battery for the Assessment of Neuropsychological Status (Randolph, 2012). Because we did not include a measure of this kind, we were unable to examine the possible relationship between

subjective memory concern and objective cognitive impairment. The inclusion of this measure produced a significant interaction in Kinzer and Suhr's (2016) study between worry and memory impairment. A future study should be sure to include an objective measure in an effort to expand upon the results of Kinzer and Suhr's that showed that people with no objective memory impairments, but high worry displayed similar concern to the people with objective memory impairments in both high and low worry.

Because of previous research that indicates exposure to people with dementia contributes to increased worry, this study asked about participants' immediate family history of a diagnosis of a form of dementia. Other than one question, no additional questions were asked to get a more complete picture of how participants might have dealt with that exposure or how it affected them. Because of the nature of family stigma that still exists around a diagnosis of dementia, particularly in individualistic cultures in the United States, future research that delves deeper into participants' exposure might lend insight into why exactly it increases worry in healthy family members.

This sample also lacks representation among different cultures present in the United States. Participants reported their race as White 90.3% of the time, with 5.1% identifying as Black or African American, and 3.9% as Asian. Given the current demographics of the United States reported by the 2021 Census Bureau, White participants are overrepresented in this study's sample (U.S. Department of Commerce, 2021). Similarly, Christianity was the most reported religion (over half of participants' reported religion). This is a lower percentage than in the general US population (Pew Research Center, 2014). Because dementia worry is a potentially culturally dependent dimension, generalizations should be made cautiously.

A broader, conceptual limitation is that stigma by itself is a very nuanced concept that incorporates stereotyping behaviors, prejudice, and discriminatory practices towards specific groups of people. Different groups, such as rich people compared to elderly people, will have unique attitudes and actions enacted upon them, in turn drastically affecting whether someone is viewed as part of the “in-group” or “out-group.” Because this current study did not break down each element of stigma towards people with dementia, it is entirely possible that the questions asked in this study do not adequately capture participants’ true feelings on the nature of stigma and dementia worry. In future studies, one way to navigate around this problem may be to conduct a study similar to this conducted one with an interview component that contains open-ended questions for participants to respond to in order to attempt to get at the true nature of their thoughts and feelings.

There may also be more to the nature of stigma that was not able to be addressed here. Stereotyping and stereotype threat are facets that help to contribute to overall stigma and impact how individuals view themselves with dementia worry. Aging stereotypes make individuals cognizant of memory issues, which in turn builds upon that dementia worry (Hummert, 2011). In a stereotype threat condition that exposes participants to aging stereotypes that specifically target cognitive performance, we might be able to observe a stronger relationship between anticipated stigma predicting an increase in dementia worry. Adding in an objective memory assessment as discussed earlier could help to broaden understanding of how individuals are impacted by the stigma that contributes to dementia worry within their lives.

## **Conclusions**

The present study sought to both replicate the results of Maxfield and Greenberg’s (2021) study, as well as expand upon the idea of anticipated stigma; anticipated stigma from work



colleagues offers the added insight into potential predictors of dementia worry. This added dimension provides more explanation for dementia worry as a concept through a stereotype content framework that focuses on the importance of competence over warmth for middle-aged people in the United States. Provided the limitations of this current study, there is little evidence to indicate that the results were erroneously impacted. These results, both confirmatory and exploratory, give insight into dementia worry and will help to provide future directions for understanding and application on stigma towards people with dementia, and dementia as a disease.

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**Table 1**

*Descriptive Statistics and Bivariate correlations for study variables*

| Variable            | <i>M</i> | <i>SD</i> | 1      | 2        | 3       | 4        | 5        | 6        | 7        | 8        | 9        | 10      | 11 |
|---------------------|----------|-----------|--------|----------|---------|----------|----------|----------|----------|----------|----------|---------|----|
| 1. Education        | 16.50    | 2.99      | --     | --       | --      | --       | --       | --       | --       | --       | --       | --      | -- |
| 2. Age              | 51.20    | 7.18      | 0.013  | --       | --      | --       | --       | --       | --       | --       | --       | --      | -- |
| 3. Family History   | 0.14     | 0.35      | 0.051  | 0.249*** | --      | --       | --       | --       | --       | --       | --       | --      | -- |
| 4. Anxiety          | 0.22     | 0.36      | -0.013 | -0.157** | 0.053   | --       | --       | --       | --       | --       | --       | --      | -- |
| 5. Present Ability  | 5.47     | 1.14      | 0.027  | 0.011    | -0.057  | 0.228*** | --       | --       | --       | --       | --       | --      | -- |
| 6. AD Likelihood    | 2.89     | 1.10      | 0.022  | 0.042    | 0.120*  | 0.257*** | 0.451*** | --       | --       | --       | --       | --      | -- |
| 7. Friends & Family | 2.08     | 1.05      | 0.037  | -0.041   | -0.020  | 0.239*** | 0.219*** | 0.291*** | --       | --       | --       | --      | -- |
| 8. Work Colleagues  | 3.69     | 1.11      | 0.104* | -0.029   | -0.008  | 0.086    | 0.129*** | 0.244*** | 0.485*** | --       | --       | --      | -- |
| 9. Warmth           | 2.70     | 0.80      | 0.038  | -0.057   | -0.051  | -0.071   | 0.076    | -0.021   | 0.251*** | -0.157** | --       | --      | -- |
| 10. Competence      | 1.65     | 0.60      | -0.03  | -0.036   | -0.105* | -0.071   | 0.093    | -0.132** | 0.170*** | 0.268*** | 0.406*** | --      | -- |
| 11. Dementia Worry  | 1.46     | 0.67      | 0.041  | -0.017   | .156**  | 0.320*** | 0.368*** | 0.659*** | 0.291*** | 0.235*** | -0.003   | -0.122* | -- |

*Note.* "Education" refers to mean years of formal education; "Family History" is a yes (1)/no (0) response for any first-degree relative with a history of dementia; "Age" refers to reported chronological age; "Anxiety" refers to the average from the anxiety subscale of the DASS; "Present Ability" refers to the average from the Present Ability subscale of the MCI; "AD Likelihood" refers to the average from the Alzheimer's Likelihood subscale of the MCI; "Friends and Family" refers to the average of anticipated stigma from Friends and Family from the CIASS; "Work Colleagues" refers to average of anticipated stigma from Work Colleagues from the CIASS; "Warmth" refers to the items on the SCM inventory directed towards dementia patients concerning feelings of warmth; "Competence" refers to the items on the SCM inventory directed towards dementia patients concerning feelings of competence; "Dementia Worry" refers to the average scores from the dementia worry scale.

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

**Table 2***Hierarchical Regression Results for Anticipated Stigma Predicting Dementia Worry*

| Variable         | <i>B</i> | 95% CI for <i>B</i> |           | <i>SE B</i> | $\beta$ | <i>R</i> <sup>2</sup> | $\Delta R^2$ |
|------------------|----------|---------------------|-----------|-------------|---------|-----------------------|--------------|
|                  |          | <i>LL</i>           | <i>UL</i> |             |         |                       |              |
| Step 1           |          |                     |           |             |         | .08                   |              |
| Constant         | 1.08***  | 0.94                | 1.21      | 0.07        |         |                       |              |
| Friends & Family | 0.19***  | 0.13                | 0.24      | 0.03        | .29***  |                       |              |
| Step 2           |          |                     |           |             |         | .10                   | .01*         |
| Constant         | 0.88***  | 0.67                | 1.09      | 0.11        |         |                       |              |
| Friends & Family | 0.15***  | 0.08                | 0.21      | 0.03        | .23     |                       |              |
| Work Colleagues  | 0.07*    | 0.01                | 0.14      | 0.03        | .12     |                       |              |

*Note.* CI = confidence interval; LL = lower limit; UL = upper limit; “Friends and Family” refers to the average of anticipated stigma from Friends and Family from the CIASS; “Work Colleagues” refers to average of anticipated stigma from Work Colleagues from the CIASS.

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

**Table 3**

*Hierarchical Regression Results for Exploratory Predictors of Dementia Worry with AD Likelihood Scale*

| Variable                    | B       | 95% CI for B |      | SE B | $\beta$ | R <sup>2</sup> | $\Delta R^2$ |
|-----------------------------|---------|--------------|------|------|---------|----------------|--------------|
|                             |         | LL           | UL   |      |         |                |              |
| Step 1                      |         |              |      |      |         | .47            |              |
| Constant                    | 0.53**  | 0.19         | 0.88 | 0.18 |         |                |              |
| Family History <sup>a</sup> | 0.14*   | 0.01         | 0.28 | 0.07 | .21*    |                |              |
| Anxiety                     | 0.28*** | 0.14         | 0.41 | 0.07 | .15***  |                |              |
| AD Likelihood               | 0.36*** | 0.31         | 0.41 | 0.02 | .59***  |                |              |
| Present Ability             | -0.03   | -0.08        | 0.01 | 0.02 | -.06    |                |              |
| Step 2                      |         |              |      |      |         | .47            | .006*        |
| Constant                    | 0.44*   | 0.08         | 0.79 | 0.18 |         |                |              |
| Family History <sup>a</sup> | 0.15*   | 0.02         | 0.28 | 0.07 | .23*    |                |              |
| Anxiety                     | 0.25*** | 0.11         | 0.39 | 0.07 | .14***  |                |              |
| AD Likelihood               | 0.35*** | 0.30         | 0.40 | 0.03 | .57***  |                |              |
| Present Ability             | -0.03   | -0.08        | 0.02 | 0.02 | -.05    |                |              |
| Friends & Family            | 0.05*   | 0.01         | 0.10 | 0.02 | .08*    |                |              |
| Step 3                      |         |              |      |      |         | .48            | .002         |
| Constant                    | 0.37    | -0.002       | 0.74 | 0.19 |         |                |              |
| Family History <sup>a</sup> | 0.15*   | 0.02         | 0.29 | 0.07 | .23*    |                |              |
| Anxiety                     | 0.26*** | 0.12         | 0.39 | 0.07 | .14***  |                |              |
| AD Likelihood               | 0.34*** | 0.29         | 0.39 | 0.03 | .56***  |                |              |
| Present Ability             | -0.03   | -0.08        | 0.02 | 0.02 | -.05    |                |              |
| Friends & Family            | 0.04    | -0.01        | 0.09 | 0.03 | .06     |                |              |
| Work Colleagues             | 0.03    | -0.02        | 0.   | 0.02 | .05     |                |              |

*Note.* CI = confidence interval; LL = lower limit; UL = upper limit; "Family History" is a response for any first-degree relative with a history of dementia; "Anxiety" refers to the average from the anxiety subscale of the DASS; "AD Likelihood" refers to the average from the Alzheimer's Likelihood subscale of the MCI; "Present Ability" refers to the average from the Present Ability subscale of the MCI; "Friends and Family" refers to the average of anticipated stigma from Friends and Family from the CIASS; "Work Colleagues" refers to average of anticipated stigma from Work Colleagues from the CIASS.

<sup>a</sup> 0 = no, 1 = yes

\* p < .05, \*\* p < .01, \*\*\* p < .001

**Table 4**

*Hierarchical Regression Results for Exploratory Predictors of Dementia Worry without AD Likelihood Scale*

| Variable                    | B        | 95% CI for B |       | SE B | $\beta$ | R <sup>2</sup> | $\Delta R^2$ |
|-----------------------------|----------|--------------|-------|------|---------|----------------|--------------|
|                             |          | LL           | UL    |      |         |                |              |
| Step 1                      |          |              |       |      |         | .20            |              |
| Constant                    | 2.29***  | 1.98         | 2.59  | 0.16 |         |                |              |
| Family History <sup>a</sup> | 0.24**   | 0.08         | 0.41  | 0.08 | .36**   |                |              |
| Anxiety                     | 0.42***  | 0.26         | 0.59  | 0.08 | .23***  |                |              |
| Present Ability             | -0.17*** | -0.23        | -0.12 | 0.03 | -.30*** |                |              |
| Step 2                      |          |              |       |      |         | .24            | .03***       |
| Constant                    | 1.95***  | 1.61         | 2.29  | 0.17 |         |                |              |
| Family History <sup>a</sup> | 0.26**   | 0.10         | 0.42  | 0.08 | .38**   |                |              |
| Anxiety                     | 0.36***  | 0.19         | 0.52  | 0.08 | .19***  |                |              |
| Present Ability             | -0.16*** | -0.21        | -0.10 | 0.03 | -.26*** |                |              |
| Friends & Family            | 0.12***  | 0.07         | 0.18  | 0.03 | .19***  |                |              |
| Step 3                      |          |              |       |      |         | .25            | .01*         |
| Constant                    | 1.74***  | 1.37         | 2.11  | 0.19 |         |                |              |
| Family History <sup>a</sup> | 0.26**   | 0.10         | 0.42  | 0.08 | .38**   |                |              |
| Anxiety                     | 0.37***  | 0.20         | 0.53  | 0.08 | .20***  |                |              |
| Present Ability             | -0.15*** | -0.20        | -0.10 | 0.03 | -.26*** |                |              |
| Friends & Family            | 0.08**   | 0.02         | 0.15  | 0.03 | .13**   |                |              |
| Work Colleagues             | 0.07*    | 0.02         | 0.13  | 0.03 | .12*    |                |              |

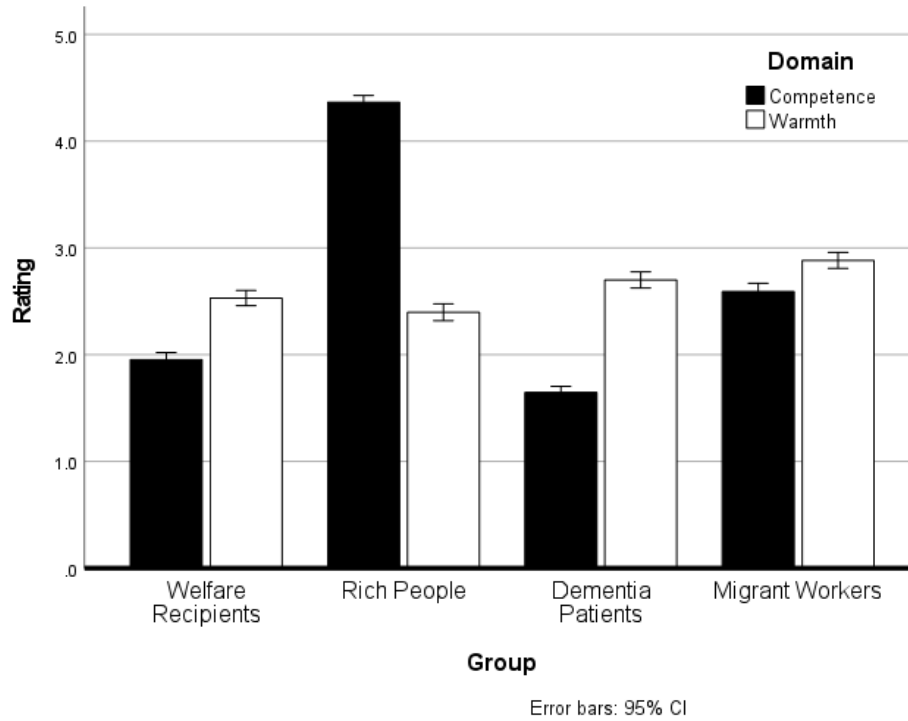
*Note.* CI = confidence interval; LL = lower limit; UL = upper limit; "Family History" is a response for any first-degree relative with a history of dementia; "Anxiety" refers to the average from the anxiety subscale of the DASS; "Present Ability" refers to the average from the Present Ability subscale of the MCI; "Friends and Family" refers to the average of anticipated stigma from Friends and Family from the CIASS; "Work Colleagues" refers to average of anticipated stigma from Work Colleagues from the CIASS.

<sup>a</sup> 0 = no, 1 = yes

\* p < .05, \*\* p < .01, \*\*\* p < .001

**Figure 1**

*Interaction between Domain and Group of the SCM Framework*



*Note.* Mean ratings were on a Likert scale of 1-5 (1= Not at all) (5= Extremely).

## Appendix A: Notice of IRB Exemption

4/19/22, 2:15 PM

Appalachian State University Mail - [External] IRB Notice - 22-0069



Taylor Leonard &lt;leonardte@appstate.edu&gt;

### [External] IRB Notice - 22-0069

1 message

IRB &lt;irb@appstate.edu&gt;

Tue, Jan 11, 2022 at 3:53 PM

To: emerylj@appstate.edu, leonardte@appstate.edu  
 Cc: bazzinidg@appstate.edu, curtinla@appstate.edu

To: Taylor Leonard  
 Psychology  
 CAMPUS EMAIL

From: IRB Administration  
 Date: 1/11/2022  
 RE: Notice of Exempt Research Determination  
 Agrants #: Currently Not Available  
 Grant Title: **Sponsors:** Sigma Xi Grants-in-Aid of Research (GIAR)

**STUDY #:** 22-0069

**STUDY TITLE:** Dementia Worry: Does anticipated stigma predict people's concerns about developing dementia

**Exemption Category:** 2.Survey, interview, public observation

**NOTE:** This project, like all exempt and non-exempt research with human subjects at Appalachian State University, is subject to other requirements, laws, regulations, policies, and guidelines of Appalachian State University and the state of North Carolina. As of August 26, 2021 and until further notice, this includes additional requirements for protections against COVID-19. Please go [here](#) for the additional requirements that you must fulfill.

This study involves no more than minimal risks and meets the exemption category or categories cited above. In accordance with the 2018 federal regulations regarding research with human subjects [45 CFR 46] and University policy and procedures, the research activities described in the study materials are exempt from IRB review.

What an exempt determination means for your project:

1. The Office of Research Protections staff have determined that your project constitutes research with human subjects, but that your research is exempt from the federal regulations governing human subjects research, per [45 CFR 46.104](#).
2. Because this research is exempt from federal regulations, the recruitment and consent processes are also exempt from Institutional Review Board (IRB) review. This means that the procedures you described and the materials you provided were not reviewed by the IRB, further review of these materials are not necessary, and that you can change the consent procedures without submitting a modification.
3. **You still need to get consent from adult subjects and, if your study involves children, you need to get assent and parental permission.** At the very least, your consent, assent, and parental permission processes should explain to research subjects: (a) the purpose, procedures, risks, and benefits of the research; (b) if compensation is available; (c) that the research is voluntary and there is no penalty or loss of benefits for not participating or discontinuing participation; and (d) how to contact the Principal Investigator (and the Faculty Advisor if the PI is a student). You can also use exempt research consent template, which accounts for all of these suggested elements of consent: <https://researchprotections.appstate.edu/human-subjects-irb/irb-forms>. **Please note that if your consent form states that the study was "approved by the IRB" this should be removed. You can replace it with a sentence that says that the study was determined to be exempt from review by IRB Administration. In addition, be sure that the number you have listed for the IRB is 828-262-2692**
4. **Special procedures and populations for which specific consent language is suggested.** Research involving children, research that uses the SONA database for recruitment, research with students at Appalachian State University, or research that uses MTurk for recruitment should use the specific language outlined by The Office of Research Protections on our [website](#).
5. **Study changes that require you to submit a modification request:** most changes to your research will not require review by the Office of Research Protections. However, the following changes require further review by our office:



4/19/22, 2:15 PM

Appalachian State University Mail - [External] IRB Notice - 22-0069

- the addition of an external funding source;
- the addition of a potential for a conflict of interest;
- a change in location of the research (i.e., country, school system, off site location);
- change in contact information for the Principal Investigator,
- the addition of non-Appalachian State University faculty, staff, or students to the research team, or
- **Changes to study procedures.** If you change your study procedures, you may need to submit a modification for further review. Changes to procedures that may require a modification are outlined in our SOP on exempt research, a link to which you can find below. Before submitting a modification to change procedures, we suggest contacting our office at [irb@appstate.edu](mailto:irb@appstate.edu) or (828) 262-2692 to confirm whether a modification is required.

**Investigator Responsibilities:** All individuals engaged in research with human participants are responsible for compliance with University policies and procedures, and IRB determinations. The Principal Investigator (PI), or Faculty Advisor if the PI is a student, is ultimately responsible for ensuring the protection of research participants; conducting sound ethical research that complies with federal regulations, University policy and procedures; and maintaining study records. The PI should review the IRB's list of PI responsibilities.

**To Close the Study:** When research procedures with human participants are completed, please send the Request for Closure of IRB Review form to [irb@appstate.edu](mailto:irb@appstate.edu).

If you have any questions, please email [IRB@appstate.edu](mailto:IRB@appstate.edu) or contact the Director of Research Protections at (828) 262-2692.

Best wishes with your research.

**Important Links for Exempt Research:**

Note: If the link does not work, please copy and paste into your browser, or visit <https://researchprotections.appstate.edu/human-subjects>.

1. Standard Operating Procedure for exempt research (#9): [https://researchprotections.appstate.edu/sites/researchprotections.appstate.edu/files/sop\\_9\\_approved\\_1.21.2019.pdf](https://researchprotections.appstate.edu/sites/researchprotections.appstate.edu/files/sop_9_approved_1.21.2019.pdf)
2. PI responsibilities: <https://researchprotections.appstate.edu/sites/researchprotections.appstate.edu/files/PI%20Responsibilities.pdf>
3. IRB forms: <http://researchprotections.appstate.edu/human-subjects/irb-forms>

**CC:**

Doris Bazzini, Psychology  
Lisa Curtin, Psychology

## Appendix B: Informed Consent

Confidential

Page 1

### Informed Consent

Before beginning this study, please read the informed consent and indicate your agreement to continue.

You are being asked to take part in a research study detailing people's attitudes and thoughts towards certain situations and topics. The study is being conducted by current master's student Taylor Leonard, supervised by Dr. Lisa Emery, in the College of Arts and Sciences at Appalachian State University.

What is this study about?

This study focuses on opinions and thoughts towards certain topics you have or may experience sometime in the future. To do this, we ask that you complete a series of surveys that asks various questions related to different opinions you have regarding certain topics. There are no right or wrong answers. We will also ask you some demographic questions and other questions about yourself.

Why is this study important? What good will the results do?

If we can learn what predicts the way people feel, and how they view certain issues, then we may be able to promote positive change in the future. More specifically, we want to learn about the reasons that they feel that way.

How many people besides me will be in this study? How much time will it take?

About 450 participants will be included in this study. The study should take no more than 20 minutes to complete.

Are there age requirements?

Yes. You must be between the ages of 40 and 65 to participate in the study.

What will I be asked to do in this study?

You will be asked to fill out a survey. Some parts of the survey are longer than others. They will ask you questions about a range of topics, including your attitudes, thoughts, and demographic information.

Will I be compensated for being in this study?

You will be given \$3.19 for participating in the current study.

What are the risks (dangers or harms) of being in this study?

There are no foreseeable risks to participating in the current study.

Will all of my answers be private?

We will not put your name on any of your answers. Instead, we will put a number on all of your answers. So, nobody will see your individual answers. We are only concerned with the combined results, not with individuals.

What are my rights as a participant?

Taking part in this study is completely voluntary. You may choose not to take part at all or decide to stop at any time, and that will be OK. The Appalachian State University Institutional Review Board (IRB) is the group that protects the rights of anyone in a research study. They review studies to be sure people in research studies are being treated fairly and the study is being researched as planned.

Who do I call if I have questions or problems?

If you have any questions about the study, you may email me at [leonardte@appstate.edu](mailto:leonardte@appstate.edu) or get in touch with my advisor, Dr. Lisa Emery at (828) 262-8941 or [emerylj@appstate.edu](mailto:emerylj@appstate.edu)

If you do not consent, please close this window to exit. In order to use your data and compensate you for your time, we require your consent. As a result, we will terminate whatever data you have provided thus far.

By clicking "submit" below, you are agreeing to the following:

- I understand the purpose of the study and what I will be asked to do.
- I understand that I may stop participating at any time.
- I agree to be in this study.

1) Please enter your unique Prolific ID here

\_\_\_\_\_

## Appendix C: Demographic Questionnaire

Confidential

Page 1

### Demographic Information

First, please give us some background information about yourself.

Please report your age in years

\_\_\_\_\_

Please indicate your race

- American Indian or Alaska Native  
 Asian  
 Black or African American  
 Native Hawaiian or Other Pacific Islander  
 White  
 Other

If indicated "Other", please provide

\_\_\_\_\_

Please indicate your ethnicity

- Hispanic or Latino or Spanish Origin  
 Not Hispanic or Latino or Spanish Origin

To which gender identity do you most identify with?

- Female  
 Male  
 Prefer Not to Say  
 Other

If indicated "Other", please provide

\_\_\_\_\_

What religion do you best identify with?

- Christian  
 Muslim  
 Jewish  
 Buddhist  
 Hindi  
 Agnostic  
 Atheist  
 Other

If you selected "other," please specify

\_\_\_\_\_

Please indicate your religious denomination

\_\_\_\_\_

Do you identify as evangelical?

- Yes  
 No

How many years have you identified with your current religion?

\_\_\_\_\_

How often do you attend church or worship services?

- Never  
 Less than once per year  
 About once or twice a year  
 Several times a year  
 About once a month  
 2-3 times a month  
 Nearly every week  
 Every week or more

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Please report how many years of formal education you have completed (typically beginning when you were 5 years old) \_\_\_\_\_

---

Are you currently employed in some capacity?  Yes  
 No

---

Have you been previously diagnosed with COVID-19?  No  
 Yes

---

If indicated 'yes' on the previous question, how would you rate the severity?

No noticeable symptoms  
 Mild Illness (e.g. symptoms with no shortness of breath)  
 Moderate Illness (e.g. O2 levels greater than or equal to 94%)  
 Severe Illness (e.g. O2 levels less than 94%)  
 Critical Illness (e.g. acute respiratory distress syndrome, exaggerated inflammatory response)

---

If you have had COVID-19, do you feel that your symptoms have persisted for weeks or months past first experiencing symptoms?  No  
 Yes

**Please indicate if you have a first-degree relative (e.g. mother, father, sibling) who has been formally diagnosed with any of the following:**

|  | Mother                   | Father                   | Sibling                  |
|--|--------------------------|--------------------------|--------------------------|
| Heart Disease                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Dementia (including Alzheimer's Disease) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Diabetes (Type I or Type II)             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Cancer                                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Chronic Lung Disease                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Chronic Kidney Disease                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |



## Appendix D: DASS-21 Survey

Confidential

Page 1

### Feelings over last week

For this next questionnaire, please read each statement and INDICATE HOW MUCH THE STATEMENT APPLIED TO YOU OVER THE PAST WEEK.

There are no right or wrong answers. Do not spend too much time on any statement.

|   | Did not apply to me at all | Applied to me to some degree, or some of the time | Applied to me to a considerable degree, or a good part of time | Applied to me very much, or most of the time |
|---|----------------------------|---|--|--|
| 1) I found it hard to wind down   | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 2) I was aware of dryness of my mouth   | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 3) I couldn't seem to experience any positive feeling at all                        | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 4) I experienced breathing difficulty   | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 5) I found it difficult to work up the initiative to do things                      | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 6) I tended to over-react to situations   | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 7) I experienced trembling (e.g., in the hands)                                     | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 8) I felt that I was using a lot of nervous energy                                  | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 9) I was worried about situations in which I might panic and make a fool of myself  | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 10) I felt that I had nothing to look forward to                                    | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 11) I found myself getting agitated   | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 12) I found it difficult to relax   | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 13) I felt down-hearted and blue  | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 14) I was intolerant of anything that kept me from getting on with what I was doing | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 15) I felt I was close to panic   | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 16) I was unable to become enthusiastic about anything                              | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 17) I felt that I wasn't worth much as a person                                     | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 18) I felt I was rather touchy  | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 19) I was aware of the action of my heart in the absence of physical exertion       | <input type="radio"/>      | <input type="radio"/>                             | <input type="radio"/>  | <input type="radio"/>                        |
| 20)   |                            |   |  |  |

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- I felt scared without any good reason
- 21) I felt that life was meaningless

## Appendix E: CIASS Survey

Confidential

Page 1

### Views of Dementia

For the next series of questions, we would like you to IMAGINE THAT YOU HAVE BEEN DIAGNOSED WITH A FORM OF DEMENTIA (for example - Alzheimer's disease, Vascular dementia, Lewy Body disease, Frontotemporal dementia).

Please answer these questions thinking about how that might affect your relationships with various people in your life.

|  | Very Unlikely         |                       |                       |                       | Very Likely           |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1) A healthcare worker will give you poor care                                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2) Your employer will assign a challenging project to someone else               | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3) A friend or family member will think that your illness is your fault          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4) A healthcare worker will blame you for not getting better                     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5) Someone at work will discriminate against you                                 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6) Someone at work will think that you cannot fulfill your work responsibilities | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 7) A healthcare worker will be frustrated with you                               | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8) A healthcare worker will think that you are a bad patient                     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 9) A friend or family member will be angry with you                              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 10) A friend or family member will not think as highly of you                    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 11) Your employer will not promote you   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12) A friend or family member will blame you for not getting better              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

## Appendix F: MOS-36 Survey

Confidential

Page 1

### General Health Survey

For this questionnaire, please complete the survey below reflecting on YOUR OWN CURRENT GENERAL HEALTH.

- 1) In general, would you say your health is:
- Excellent  
 Very Good  
 Good  
 Fair  
 Poor
- 2) Compared to one year ago, how would you rate your health in general now?
- Much better now than one year ago  
 Somewhat better now than one year ago  
 About the same  
 Somewhat worse now than one year ago  
 Much worse now than one year ago

**The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

- |  | Yes, limited a lot    | Yes, limited a little | No, not limited at all |
|--|-----------------------|-----------------------|------------------------|
| 3) Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  |
| 4) Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  |
| 5) Lifting or carrying groceries   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  |
| 6) Climbing several flights of stairs  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  |
| 7) Climbing one flight of stairs   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  |
| 8) Bending, kneeling, or stooping  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  |
| 9) Walking more than a mile  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  |
| 10) Walking several blocks   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  |
| 11) Walking one block  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  |
| 12) Bathing or dressing yourself   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  |

**During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

- |   | Yes                   | No                    |
|---|-----------------------|-----------------------|
| 13) Cut down the amount of time you spent on work or other activities | <input type="radio"/> | <input type="radio"/> |
| 14) Accomplished less than you would like                             | <input type="radio"/> | <input type="radio"/> |
| 15) Were limited in the kind of work or other activities              | <input type="radio"/> | <input type="radio"/> |
| 16)   |                       |                       |



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Had difficulty performing the work or other activities (for example, it took extra effort)

**During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

- |  | Yes  | No                    |
|--|--|-----------------------|
| 17) Cut down the amount of time you spent on work or other activities  | <input type="radio"/>  | <input type="radio"/> |
| 18) Accomplished less than you would like  | <input type="radio"/>  | <input type="radio"/> |
| 19) Didn't do work or other activities as carefully as usual   | <input type="radio"/>  | <input type="radio"/> |
| 20) During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? | <input type="radio"/> Not at all<br><input type="radio"/> Slightly<br><input type="radio"/> Moderately<br><input type="radio"/> Quite a bit<br><input type="radio"/> Extremely                     |                       |
| 21) How much bodily pain have you had during the past 4 weeks?   | <input type="radio"/> None<br><input type="radio"/> Very mild<br><input type="radio"/> Mild<br><input type="radio"/> Moderate<br><input type="radio"/> Severe<br><input type="radio"/> Very Severe |                       |
| 22) During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?   | <input type="radio"/> Not at all<br><input type="radio"/> A little bit<br><input type="radio"/> Moderately<br><input type="radio"/> Quite a bit<br><input type="radio"/> Extremely                 |                       |

**These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.**

**How much of the time during the past 4 weeks...**

- |   | All of the time       | Most of the time      | A good bit of the time | Some of the time      | A little of the time  | None of the time      |
|---|-----------------------|-----------------------|------------------------|-----------------------|-----------------------|-----------------------|
| 23) Did you feel full of pep?   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 24) Have you been a very nervous person?                                | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 25) Have you felt so down in the dumps that nothing could cheer you up? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 26)   |                       |                       |                        |                       |                       |                       |

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- |     |                                     |                       |                       |                       |                       |                       |                       |
|-----|-------------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
|     | Have you felt calm and peaceful?    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 27) | Did you have a lot of energy?       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 28) | Have you felt downhearted and blue? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 29) | Did you feel worn out?              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 30) | Have you been a happy person?       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 31) | Did you feel tired?                 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

- 
- 32) During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?
- All of the time  
 Most of the time  
 Some of the time  
 A little of the time  
 None of the time

| How TRUE or FALSE is each of the following statements for you. |                       |                       |                       |                       |                       |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
|  | Definitely true       | Mostly true           | Don't know            | Mostly false          | Definitely false      |
| 33)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 34)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 35)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 36)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

- |  | Definitely true       | Mostly true           | Don't know            | Mostly false          | Definitely false      |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 33) I seem to get sick a little easier than other people | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 34) I am as healthy as anybody I know                    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 35) I expect my health to get worse                      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 36) My health is excellent                               | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

## Appendix G: Dementia Worry Survey

Confidential

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### Concerns about Dementia

Please indicate the extent to which you agree or disagree with each statement. Provide the answer that is right for you by selecting the answer choice that best describes your beliefs. For example, if you strongly disagree with the statement, you would select "not at all typical of me". If you strongly agree with the statement, you would select "very typical of me". If you are neutral, you would select the answer choice that falls in the middle.

|  | Not at all typical<br>of me |                       |                       |                       | Very typical of<br>me |
|--|-----------------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1) I know I shouldn't worry about developing dementia, but I just cannot help it                                 | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2) I find it difficult to control my worries about developing dementia   | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3) When I can't remember something, I find myself wondering whether I have dementia                              | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4) My worries about dementia overwhelm me  | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5) More often than not, I find my thoughts returning to concerns that I have dementia                            | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6) When I hear about someone having dementia, I start to worry about having it myself                            | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 7) When I am not distracted, I find my thoughts focusing on my own cognitive changes and concerns                | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8) Even though I know it doesn't help to focus on it, I can't help thinking about whether or not I have dementia | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 9) Once I start worrying about dementia, I just cannot stop  | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 10) Sometimes when trying to go to sleep, I find my thoughts drift to my concerns about having dementia          | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 11) When I forget a word that I want to say, my thoughts immediately turn to dementia                            | <input type="radio"/>       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12)  |                             |                       |                       |                       |                       |

*Confidential*

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I think I probably worry more  
about dementia than other  
people my same age

## Appendix H: MCI Survey

Confidential

Page 1

### Concerns about Memory

This is a questionnaire about your memory. Please indicate the extent to which you agree or disagree with each statement. Provide the answer that is right for you by selecting the answer choice that best describes your beliefs. For example, if you strongly disagree with the statement, you would select "strongly disagree". If you strongly agree with the statement, you would select "strongly agree". If you are neutral, you would select "neutral".

|  | Strongly disagree     | Disagree              | Slightly disagree     | Neutral               | Slightly agree        | Agree                 | Strongly agree        |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1) There's not much I can do to keep my memory from going downhill.                        | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2) I can remember the things I need to.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3) I can't seem to figure out what to do to help me remember things.                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4) No matter how much I use my memory, it is bound to get worse as I get older.            | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5) Alzheimer's disease is a common problem among the elderly.                              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6) As I get older I'll need to rely on others to remember things for me.                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 7) If I work at it, I can improve my memory  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8) I'm not good at remembering things.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 9) If I use my memory a lot, it will stay in shape, just like my muscles do if I exercise. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 10) I can find ways to improve my memory.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 11) When I forget something I am apt to think I have Alzheimer's disease.                  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12) I can't remember things, even if I want to.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 13) I think there's a good chance I will get Alzheimer's disease.                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 14) If I use my memory often I won't lose it.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 15)  |                       |                       |                       |                       |                       |                       |                       |

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- As I get older I won't have to rely on others to remember things for me.
- 16) I can think of strategies to help me keep up my memory.
- 17) If I want to have a good memory I need to have others to help me remember.
- 18) I sometimes think that I have Alzheimer's disease.
- 19) When it comes to memory, there is no way I can make up for the losses that come with age.

## Appendix I: Stereotype Content Model Survey

Confidential

Page 1

### Societal Attitudes

For this final survey, we are interested in what societal attitudes are about different groups of people.

For each set of questions, please rate how members of the indicated group are viewed by American society.

We are not interested in your personal beliefs, but in how you think they are viewed by others.

**For the following questions, please rate how WELFARE RECIPIENTS are viewed by American society.**

|  | Not at all            |                       |                       |                       | Extremely             |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1) As viewed by society, how competent are members of this group?    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2) As viewed by society, how confident are members of this group?    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3) As viewed by society, how independent are members of this group?  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4) As viewed by society, how competitive are members of this group?  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5) As viewed by society, how intelligent are members of this group?  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6) As viewed by society, how tolerant are members of this group?     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 7) As viewed by society, how warm are members of this group?         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8) As viewed by society, how good natured are members of this group? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 9) As viewed by society, how sincere are members of this group?      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**For the following questions, please rate how WEALTHY PEOPLE are viewed by American society.**

|  | Not at all            |                       |                       |                       | Extremely             |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 10) As viewed by society, how competent are members of this group? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 11)  |                       |                       |                       |                       |                       |



Confidential

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- |   |                       |                       |                       |                       |                       |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| As viewed by society, how confident are members of this group?        | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12) As viewed by society, how independent are members of this group?  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 13) As viewed by society, how competitive are members of this group?  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 14) As viewed by society, how intelligent are members of this group?  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 15) As viewed by society, how tolerant are members of this group?     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 16) As viewed by society, how warm are members of this group?         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 17) As viewed by society, how good natured are members of this group? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 18) As viewed by society, how sincere are members of this group?      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**For the following questions, please rate how DEMENTIA PATIENTS are viewed by American society.**

- |  | Not at all            |                       |                       |                       | Extremely             |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 19) As viewed by society, how competent are members of this group?   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 20) As viewed by society, how confident are members of this group?   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 21) As viewed by society, how independent are members of this group? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 22) As viewed by society, how competitive are members of this group? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 23) As viewed by society, how intelligent are members of this group? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 24)  |                       |                       |                       |                       |                       |



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- |   |                       |                       |                       |                       |                       |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| As viewed by society, how tolerant are members of this group?         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 25) As viewed by society, how warm are members of this group?         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 26) As viewed by society, how good natured are members of this group? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 27) As viewed by society, how sincere are members of this group?      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**For the following questions, please rate how MIGRANT WORKERS are viewed by American society.**

- |   | Not at all            |                       |                       |                       | Extremely             |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 28) As viewed by society, how competent are members of this group?    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 29) As viewed by society, how confident are members of this group?    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 30) As viewed by society, how independent are members of this group?  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 31) As viewed by society, how competitive are members of this group?  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 32) As viewed by society, how intelligent are members of this group?  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 33) As viewed by society, how tolerant are members of this group?     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 34) As viewed by society, how warm are members of this group?         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 35) As viewed by society, how good natured are members of this group? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 36) As viewed by society, how sincere are members of this group?      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

### **Vita**

Taylor E. Leonard was born on June 13, 1997 in Boca Raton, FL, to Cynthia J. DeFrancisco and John K. Leonard. Taylor graduated from Bearden High School in 2015. In the fall of 2015, she began her undergraduate degree at Maryville College where she earned a Bachelor of Science degree in Neuroscience-Psychology under the guidance of Dr. Lori Schmied. She graduated from Maryville in spring 2019 and took a year to work as a Cognitive Tester at The Pat Summitt Clinic in Knoxville, TN. The Pat Summitt Clinic specializes in care for Alzheimer's Disease and related dementias and was where Taylor decided she wanted to continue to pursue research with older people and the implications of aging on memory.

In the fall of 2020, Taylor enrolled in Appalachian State University's Experimental Psychology Master of Arts program. She is expected to graduate in August 2022. During her time at Appalachian State, Taylor researched anxiety over developing dementia and the associated stigma surrounding it under the guidance of Dr. Lisa Emery. She presented research at national conferences and received internal research and travel grants. In fall 2022, Taylor will begin her studies toward a doctorate degree in lifespan and developmental psychology at North Carolina State University. She will be mentored by Dr. Daniel Grühn. Her research will focus on older adults and how emotion is affected by memory changes as people age.