Anticipated Stigma and Dementia-Related Anxiety in Middle-Aged and Older Adults

Molly Maxfield[1], **Jeff Greenberg**[2]

[1]Department of Psychology, University of Colorado, Colorado Springs, CO, USA

[2]Department of Psychology, University of Arizona, Tucson, AZ, USA

Abstract

Heightened awareness and perceived negativity of Alzheimer's disease and related dementias (ADRD) may increase health-related concerns about developing ADRD, also called dementia-related anxiety. Anticipating greater levels of ADRD stigma was expected to be associated with greater dementia-related anxiety. Middle-aged and older adults ($N = 183$, aged 40–80, $M = 59.57$) responded to online questionnaires about anticipated ADRD stigma, ADRD exposure, dementia-related anxiety, and potential psychosocial correlates of dementia-related anxiety. Multivariate regression analyses revealed that self-perceived ADRD risk, ADRD exposure, and anticipated stigma remained significantly associated with dementia-related anxiety, after controlling for demographic variables. Reducing ADRD stigma may ease dementia-related anxiety, an area for future research.

Keywords

dementia-related anxiety; anticipated ADRD stigma; self-perceived dementia risk; ADRD exposure

Even the healthiest aging process involves changes that affect physical functioning (e.g., worsening eyesight, joint pain) and emotional functioning (e.g., death of friends or spouse), which may negatively influence one's daily life. However, there is something uniquely distressing about declines in one's own cognitive functioning. Within the scope of "normal cognitive aging," occasional forgetfulness may be expected (see Salthouse, 2010, for an overview) but does not impede daily life. With neurodegenerative diagnoses, however, cognitive decline intensifies over time. Alzheimer's disease (AD) is the most recognizable dementia, but other, less familiar diagnoses (e.g., vascular dementia, frontotemporal dementia, dementia with Lewy Bodies, etc.) have similarly negative effects on functioning. As the fifth leading cause of death among Americans aged 65 and older, Alzheimer's disease and related dementias (ADRD) are common, and increasing age is the biggest risk factor

Molly Maxfield, College of Nursing and Health Innovation, Arizona State University, 500 N. 3rd St, Phoenix, AZ 85004, USA, molly.maxfield@asu.edu.

Molly Maxfield, Ph.D. is now at the Edson College of Nursing and Health Innovation at Arizona State University.

(Alzheimer's Association, 2018). Early stages of dementia may require increased reminders and support to remain independent, but middle to late stages of dementia typically result in loss of independence, eventuating the need for continuous care for most, if not all, aspects of daily life. Advanced forms of these diseases also take a tremendous toll on the individual's family and caregivers (for an overview, see Zarit et al., 2019). In light of the prevalence, negative perceptions of ADRD, significant life changes, and lack of control associated with neurodegenerative disorders, ADRD present a potentially anxiety-provoking set of diagnoses.

Dementia-related anxiety involves the fear that one has or will receive a dementia diagnosis, and this anxiety can occur within individuals of any age or cognitive status (Kessler, Bowen, Baer, Frölich, & Wahl, 2012). Dementia-related anxiety may range from occasional, passing worry to more severe forms, involving preoccupation with cognitive functioning and aspects of one's life negatively influenced by ADRD. Highlighting its role in daily life, dementia-related anxiety is associated with anxiety (French, Floyd, Wilkins, & Osato, 2012) and depressive symptoms (Cui, Maxfield, & Fiske, in press), particularly among those with ADRD exposure (Kinzer & Suhr, 2016). Concern about ADRD appears to be prevalent, with almost one third of US adults identifying AD as their most feared diagnosis (MetLife Foundation, 2011). Although some dementia-related anxiety is associated with the tendency to monitor symptoms and seek out ADRD testing (e.g., Maxfield, Cui, Roberts, & Fiske, in press), the differentiation between adaptive and maladaptive levels of dementia-related remains unclear.

In their conceptual overview, Kessler and colleagues (2012) offer three possible antecedents of dementia-related anxiety: negative perceptions of ADRDs and their consequences, greater perceived ADRD risk, and perceived lack of control. The present study focused on the social consequences of ADRD, specifically on the anticipated stigma if one were to be diagnosed. The concept of anticipated stigma involves concern about being treated differently based on one's diagnosis and originates from work concerning treatment of older adults' depression in primary-care setting (Sirey, Franklin, McKenzie, Ghosh, & Raue, 2014). Sirey and colleagues found that older adults with depressive symptoms who anticipate stigma because of their diagnosis were less likely to receive mental-health referrals; further, even when enrolled in treatment, individuals anticipating greater stigma did not experience as much symptom reduction (Raeifar, Halkett, Lohman, & Sirey, 2017).

One may anticipate greater stigma when a diagnosis and its associated outcomes are perceived negatively, as in the case of dementia. Many negative stereotypes about older adults relate to poor or declining cognitive functioning (for a review, see Kite, Stockdale, Whitley, & Johnson, 2005). In a systematic review, Werner (2014) identified common themes in dementia stigmatization, including the severity and disruptive nature of the cognitive changes occurring, lack of attention to personal appearance and hygiene, and negative emotions expressed toward individuals with dementia (e.g., shame, impatience, ridicule). The primary positive emotion evoked by individuals diagnosed with dementia was pity, reflecting a benevolent form of stigmatization that can be damaging in its own regard. In a vignette study, adult participants expected an individual diagnosed with AD to experience stigma, including less emotional support and social interaction as well as greater

likelihood of discrimination (e.g., denial of insurance or exclusion from decision making); anticipated stigma was most evident among participants who perceived AD as a mental illness (Stites et al., 2018). Other vignette studies revealed that severity and prognosis are powerful predictors for distancing and stigmatization. Portrayal of more severe symptoms resulted in greater social distancing compared to mild to moderate symptoms (Werner, 2005), and belief that dementia symptoms would get worse resulted in expectations of more discrimination, more social distancing, and more pity toward the target compared to targets whose symptoms were expected to stay the same or improve (Johnson, Harkins, Cary, Sankar, & Karlawish, 2015). A sample of German adults revealed that fear is the primary reaction toward individuals diagnosed with ADRD (von dem Knesebeck, Angermeyer, Lüdecke, & Korahl, 2014). These reviews and studies suggest that ADRD stigmatization is prevalent among the general population and likely contributes to anticipatory anxiety about developing ADRD. Therefore, it was hypothesized that people who anticipated more ADRD stigma would also report greater dementia-related anxiety.

Research Objectives

Individuals with and without dementia diagnoses experience, recognize, and/or anticipate stigma associated with ADRD; therefore, the study focused on the relationship between anticipated ADRD stigma and dementia-related anxiety. Based on Kessler and colleagues' (2012) suggestion that perceived risk and perceived control also contribute to dementia-related anxiety, we also examined these variables in a survey study of middle-aged and older adults.

Given the negative perceptions of ADRD, adults anticipating greater ADRD stigma were expected to report higher levels of dementia-related anxiety. Similarly, individuals with greater self-perceived ADRD risk and lower perceived control (via low-internal and high-external locus of control) were expected to report higher levels of dementia-related anxiety. The positive relationship between self-perceived ADRD risk and dementia-related anxiety is generally well established (e.g., Bowen, Kessler, & Segler, 2019), though sometimes only significant among those with personal (genetic and nongenetic) exposure (e.g., Kinzer & Suhr, 2016). However, there is less evidence concerning perceived control, and what does exist appears largely focuses on control specific to memory. For example, at least two known studies demonstrate the negative relationship between dementia-related anxiety and memory control (e.g., Bowen et al., 2019; Kinzer & Suhr, 2016), whereas the present study assessed locus of control more broadly. The present study also examined the roles of demographic factors (age, education, sex), self-perceived physical health, ADRD exposure (genetic and nongenetic), and a measure of expectations about aging (Sarkisian, Steers, Hays, & Mangione, 2005). Previous results for demographic variables are somewhat inconsistent, with some research reporting that women endorsed greater dementia-related anxiety (e.g., Bowen et al., 2019; Cutler & Hodgson, 2001) and others not (e.g., Kinzer & Suhr, 2016; Molden & Maxfield, 2017), and some studies reporting a positive relationship with age (e.g., Cui et al., in press, though Bowen et al. (2019) report a quadratic relationship with age in a lifespan sample) and others do not (e.g., Kinzer & Suhr, 2016). Some studies find that more education is associated with lower dementia-related anxiety (e.g., Roberts & Maxfield, 2018) and others do not (e.g., Cutler & Hodgson, 2001). Therefore, there were no specific

hypotheses for the demographic variables, but they were included nevertheless to add to the existing literature on these variables. Hypotheses regarding expectations about aging were more tentative, although we expected that positive expectations about aging would be negatively associated with dementia-related anxiety, particularly for cognitive (versus physical or emotional) expectations about aging. Lastly, we assessed social desirability (Reynolds, 1982). In a recent study of ageist attitudes and dementia-related anxiety, greater tendency toward social desirability was associated with reports of lower hostile ageism and lower dementia-related anxiety among adults of all ages (Yun & Maxfield, in press). Therefore, greater social desirability was expected to be associated with lower reported dementia-related anxiety.

Method

Procedure

Study procedures received approval from the Institutional Review Board. Participants recruited via Qualtrics research panels system completed the study online. Participants provided their age before the study; individuals under age 40 could not continue. An age cutoff of 40 and above was used to ensure participants were middle-aged and older (e.g., Cohen, 2012), given the increased relevance of ADRD and dementia-related anxiety for middle-aged (e.g., Cutler & Hodgson, 2001) and older adults (e.g., Bowen et al., 2019). After reading the study introduction, participants provided informed consent before beginning the survey. Study completion took an average of 18 minutes. After concluding the study, participants read a written debriefing including researchers' contact information. Participants were compensated $1.00, in the form of gift certificates, cash, airline points, or other bonuses, per Qualtrics policy. Participants completed the study measures in the order described.

Measures

Dementia-Related Anxiety—The modified 12-item Dementia Worry Scale (DWS; Kinzer & Suhr, 2016) assessed dementia-related anxiety. The modified scale included AD specifically because it is the most common dementia, and most adults have some familiarity with or awareness of AD. For example, the item "My worries about dementia overwhelm me" was changed to "My worries about Alzheimer's disease and other forms of dementia overwhelm me." Participants indicate agreement with statements on a 5-point scale; higher sum scores indicate greater dementia-related anxiety. Internal reliability was strong (α = .95).

Social Desirability—A 13-item version of the Marlowe-Crowne Social Desirability Scale (Reynolds, 1982) assessed tendency to present in an overly positive manner. Participants indicate whether each statement is true or false for them personally; socially desirable responses were scored as one point. For example, a true response to the item "I'm always willing to admit it when I make a mistake" is scored as socially desirable. Higher sum scores indicate greater socially desirable bias. Internal reliability was low (α = .70).

Anticipated Cost of Stigma—The original Anticipated Cost of Stigma Scale (ACSS) assesses costs of stigma anticipated with a depression diagnosis (Sirey et al., 2014). The 7-item scale was altered to assess stigma associated with ADRD (e.g., "If I were diagnosed with Alzheimer's disease or another dementia, I would be concerned that my friends and family may exclude me."). Participants rate their agreement on a scale from 1 (*strongly disagree*) to 4 (*strongly agree*); higher mean scores indicate greater anticipated ADRD stigma. Internal reliability was strong (α = .91).

Locus of Control—The 24-item Levenson Locus of Control scale includes three subscales: internality (e.g., "My life is determined by my own actions."), powerful others (e.g., "My life is chiefly controlled by powerful others."), and chance (e.g., "I have often found that what is going to happen will happen."), with the latter two representing forms of external control (Levenson, 1981). Participants indicate their agreement with statements on a scale of −3 to 3. After rescoring per Levenson's instructions (adding a constant of 24 to each subscale to eliminate negative scores), subscale scores range from 0 to 48; higher scores indicate higher levels of control (internal or external). The internality subscale had low reliability (α = .65), whereas powerful others (α = .82) and chance (α = .81) subscales had acceptable reliability.

Expectations About Aging—Participants next completed the 12-item Expectations Regarding Aging Scale (ERA-12; Sarkisian et al., 2005), indicating agreement with statements on a scale of 1 (*definitely true*) to 4 (*definitely false*). This scale reflects perceptions and expectations about aging (e.g., "I expect that as I get older, I will become more forgetful.") and includes three subscales: physical health, mental health, and cognitive function. Higher mean scores indicate more positve aging expectations. Internal reliability for the overall scale was strong (α = .84) and somewhat lower for the subscales (physical α = .71, mental α = .72, and cognitive α = .81).

ADRD Exposure—Next, participants answered six yes/no questions about ADRD exposure: have/had a genetic relative with ADRD, have/had a nongenetic relative with ADRD, have/had a close friend with ADRD, serving/served as a caregiver for someone with ADRD, know/have known a caregiver for someone with ADRD, and work/have worked with people diagnosed with ADRD. Participants were categorized as no exposure (answered "no" to all six questions), nongenetic exposure (indicated at least one type of exposure but did not have genetic relative with ADRD), or genetic exposure (indicated a genetic relative with ADRD; within this group, individuals may also indicate other types of nongenetic exposure).

Demographics—Participants provided basic demographic information and responses to items assessing self-perceived general health (1 = *poor* to 5 = *excellent*) and self-perceived risk of developing dementia within one's lifetime (1 = *no risk at all* to 5 = *very high risk*).

Attention Checks—Because data collection occurred online, two attention checks were included to help identify random or inattentive responders. An early attention check instructed participants to select a specific response option. The second attention check occurred in the middle of the study and appeared to be a checklist of adjectives potentially describing participants, but a sentence in the instructions indicated, "To show that you have

read the instructions, please ignore the statement below and click on the 'None of the above' option as your only answer."

Statistical Analyses

Linear regression was used to test the primary hypothesis that anticipated cost of stigma of ADRD would be associated with dementia-related anxiety. Next, hierarchical regression was used to determine whether the relationship remained after controlling for demographic variables (Step 1 included age, years of education, sex, relationship status, and self-perceived physical health) and ADRD variables (Step 2 included ADRD exposure and self-perceived ADRD risk). Continuous independent variables were centered around the mean; categorical variables were dummy coded (sex: *female* = 1, *male* = 0; relationship status: 1 = *married/partnered*, 0 = *single, divorced, widowed, other*, ADRD exposure: 0 = *no ADRD exposure*, 1 = *nongenetic ADRD exposure*, and 2 = *genetic ADRD exposure*). For the primary hypothesis, a p value of less than .05 was used to determine statistical significance.

Secondary analyses included bivariate correlations to determine whether expectations about aging and locus of control were associated with dementia-related anxiety. One-way analyses of variance (ANOVA) were used to identify differences between individuals without ADRD exposure, with nongenetic ADRD exposure, and with genetic ADRD exposure. Because these were secondary analyses and included multiple comparisons, a more stringent p value of .01 was used, in an effort to reduce potential for Type I error. Standard assumptions were met, unless otherwise noted.

Results

Participants

A total of 639 participants started the study; 11 did not move beyond the age screen, and an additional 10 indicated that they would not provide their best answers (a screening question included by Qualtrics). Seventy-two participants failed the first attention check (M_{age} = 56.03, SD = 10.95; 24 women), and 335 failed the second attention check (M_{age} = 58.96, SD = 10.54; 140 women), raising questions about the validity of their data. These exclusions left 211 of participants with complete data. An additional attention check was inadvertently included with the repetition of an exposure question ("I have (or had) a nongenetic relative diagnosed with Alzheimer's disease or another type of dementia."); 28 participants (M_{age} = 57.86, SD = 10.73; 13 women) had conflicting answers for the identical question raising concerns about the validity of their responses. After these exclusions, the remaining 183 participants were included in reported analyses; see Table 1 for participant characteristics.

Although this conservative approach resulted in the exclusion of an unexpectedly high number of potential participants, individuals included in analyses were believed to be fully engaged in study procedures. Unfortunately, it is also likely that some participants responding in a valid manner were excluded, a limitation addressed in the discussion.

Participant Characteristics

Participants ranged in age from 40 to 80; the sample was 50.8% female ($n = 93$). The majority of respondents identified as caucasian/white ($n = 158$, 86.3%); other participants identified as Native American/Alaska Native ($n = 12$, 6.6%), Asian/Asian-American ($n = 4$, 2.2%), African-American/Black ($n = 5$, 2.7%), or selected "other" and indicated more than one racial category ($n = 4$, 2.2%). Five participants (2.7%) identified as Hispanic, 177 identified as non-Hispanic (96.7%); 1 participant indicated "unknown" for this item. One hundred one participants reported being married or partnered (55.2%); other participants reported being single ($n = 27$, 14.8%), divorced ($n = 34$, 18.6%), widowed ($n = 19$, 10.4%), or "other" ($n = 2$, 1.1%).

Anticipated Cost of Stigma and Dementia-Related Anxiety

Linear regression revealed that higher anticipated ADRD stigma was associated with greater dementia-related anxiety, $F(1, 181) = 16.90$, $p < .001$; ACSS accounted for 8.5% of the variance in dementia-related anxiety. Hierarchical regression tested the primary hypothesis after controlling for demographic variables (Step 1) and ADRD variables (Step 2). Finally, Step 3 included anticipated ADRD stigma. Step 1 was significant, $F(5, 176) = 6.66$, $p < .001$, and accounted for 15.9% of the variance in dementia-related anxiety. Within Step 1, greater self-perceived physical health was associated with lower dementia-related anxiety, and being female was associated with greater levels of dementia-related anxiety. Within Step 2, self-perceived ADRD risk was associated with dementia-related anxiety and ADRD exposure was not; the amount of dementia-related anxiety variance accounted for increased significantly, $F(2, 174) = 46.15$, $p < .001$. The gender difference in dementia-related anxiety was no longer significant in Step 2, but the negative relationship between self-perceived physical health and dementia-related anxiety remained significant, and older age was negatively associated with dementia-related anxiety. Step 2 accounted for an additional 29.1% of variance in reported dementia-related anxiety (45.1% total). Within Step 3, anticipated ADRD stigma was associated with dementia-related anxiety, and the amount of dementia-related anxiety variance accounted for was significantly greater, $F(1, 173) = 4.78$, $p = .01$. Female participants reported greater dementia-related anxiety than males, and self-perceived health and self-perceived ADRD risk had significantly negative and positive relationships, respectively; age was no longer significantly associated with dementia-related anxiety. Step 3 accounted for an additional 2.3% of variance in dementia-related anxiety (47.3% total) (see Table 2).

Secondary Analyses

Psychosocial Correlates of Dementia-Related Anxiety—Using bivariate correlation, several significant relationships were identified between variables of interest, partially supporting tentative hypotheses. A p value of .01 was adopted to set a higher threshold for statistical significance due to the large number of possible correlations. Greater dementia-related anxiety was associated with less positive expectations about aging, greater belief in powerful others and chance (external loci of control), and lower social desirability. Upon examining the ERA-12 subscales, physical expectations about aging were not associated with dementia-related anxiety ($r = -.11$, $p = .15$), whereas more positive

expectations about aging specific to mental ($r = -.31$, $p < .001$) and cognitive ($r = -.30$, $p < .001$) health were negatively associated with dementia-related anxiety. Contrary to expectations, dementia-related anxiety was not associated with lower internal locus of control (Table 3).

ADRD Exposure—Group differences between participants with genetic ADRD exposure ($n = 62$, 33.9%), nongenetic ADRD exposure ($n = 55$, 30.1%), and without ADRD exposure ($n = 66$, 36.1%) were examined using ANOVA. Significant group differences were found for dementia-related anxiety, $F(2, 180) = 5.13$, $p = .007$, $_{partial}\eta^2 = .05$, and self-perceived ADRD risk, $F(2, 180) = 18.04$, $p < .001$, $_{partial}\eta^2 = .17$. The groups did not differ in age, self-perceived health, years of education, expectations about aging, anticipated ADRD stigma, social desirability bias, or locus of control (see Table 1). The assumption of homogeneity of variance was violated for dementia-related anxiety, anticipated cost of stigma, expectations about aging, and social desirability. After square root and multiplicative inverse transformations, assumptions of homogeneity were still violated in all four cases. ANOVAs were significant for transformed and raw scores; therefore, raw scores are listed for ease of interpretation.

Discussion

Greater ADRD prevalence rates combined with negative stereotypes associated with these disorders are likely to result in occasional anxiety about developing dementia. To the authors' knowledge, the present study was the first to assess the role of anticipated ADRD stigma in dementia-related anxiety. Supporting the primary hypothesis, individuals anticipating greater ADRD stigma also indicate greater dementia-related anxiety. After controlling for several demographic variables (sex, relationship status, age, education, and general health) as well as ADRD exposure and self-perceived ADRD risk, this relationship remained significant, though the amount of variance explained by anticipated ADRD stigma was reduced from 8.5% to 2.3%. Additionally, being female and having greater self-perceived ADRD risk were associated with greater dementia-related anxiety, and greater self-perceived health was associated with lower dementia-related anxiety.

Research clearly establishes the stigmatization experienced by those diagnosed with ADRD (e.g., Patterson, Clarke, Wolverson, & Moniz-Cook, 2018), the cognitive focus of negative age-related stereotypes (e.g., Kite et al., 2005), and the impact that negative stereotypes of older adults' cognitive status can have on objective cognitive functioning (e.g., Fresson, Dardenne, Geurten, & Meulemans, 2017) and dementia-related anxiety (Molden & Maxfield, 2017). The present results establish that anticipating changes in how people treat you following a dementia diagnosis is also associated with dementia-related anxiety.

Self-perceived ADRD risk was a significant predictor of dementia-related anxiety, representing a sizable portion of the variance. In the present study, the accuracy of participants' risk assessments cannot be discerned. Self-perceived ADRD risk was greater among participants reporting genetic ADRD exposure, which may reflect accurate awareness of a genetic component with AD (e.g., McMurtray et al., 2006) or an inaccurate assumption that other types of dementia are genetically determined. In previous studies,

nongenetic exposure was linked to marginally greater levels of dementia-related anxiety compared to individuals without any dementia exposure (e.g., Kinzer & Suhr, 2016), but that marginal difference was not observed here. It may be that the larger ($N = 183$ versus $N = 100$) and slightly younger ($M = 59.57$, $SD = 9.64$ versus $M = 69.22$, $SD = 8.50$) sample in the current study contributed to differences in results. Perhaps more significantly though may be the sampling procedures; Kinzer and Suhr's participants were part of an ongoing study including assessments of dementia worry and objective cognitive functioning, compared to the present study with middle-aged and older adults completing a single online questionnaire. An ongoing study of cognitive functioning and related attitudes may have attracted participants particularly interested and invested in their cognitive well-being.

Additionally, the modification of the Dementia Worry Scale for the present study, which included Alzheimer's disease and related dementias rather than "dementia," may also have affected results. Terminology changes were made following instances during debriefings of older participants in previous studies stating that they did not worry about dementia but did worry about getting something like AD, highlighting the important issue of dementia literacy. The modified scale helped ensure recognition of ADRD and displayed strong internal consistency ($\alpha = .95$, comparable to Kinzer & Suhr's $\alpha = .91$). A comparison of the scores from the present sample with those of Kinzer and Suhr's (2016) shows that participants with genetic exposure were roughly equivalent (23.94 versus 22.60), and that participants in the present study with nongenetic exposure (20.33 versus 17.36) and no ADRD exposure (18.63 versus 14.20) reported higher dementia-related anxiety. It is possible that greater recognition of Alzheimer's disease in the current modified scale contributed to these differences, but additional research is needed to confirm this hypothesis and provide additional support for the modified scale's psychometric properties.

The full model accounts for 47.3% of the variance of dementia-related anxiety in our sample. Other researchers (Bowen et al., 2019) who examined predictors of this type of anxiety reported being able to account for up to 53.3% of variance associated with dementia-related anxiety. Although the variables measured contribute to dementia-related anxiety, there is plenty of variance not accounted for by our predictor variables. Thus, research including other variables warrant consideration. We can only speculate at this point what they might be, but neuroticism is a likely candidate, and so may be self-esteem, which tends to be inversely correlated with anxiety.

Limitations and Future Directions

This cross-sectional study does not establish causality, and questions remain about the development and maintenance of dementia-related anxiety. It may be that attitudes developed in early life lead to long-standing negative views of aging, leaving middle-aged and older adults more prone to negative expectations about aging, anticipated stigma related to disorders common in late life, and dementia-related anxiety. Indeed, aging-related attitudes in early mid-life predict diverse aspects of aging in later life, highlighting the long-term influence of subjective views and attitudes on objective outcomes (for an overview, see Levy, 2009). To determine the order of effects, a longitudinal study is needed.

Of additional concern, the sample primarily identified as caucasian/white. A qualitative study of dementia caregivers highlights the potential for differences in ADRD stigma based on racial and ethnic identities: though minority (e.g., African American, Chinese-American, and Hispanic-American) caregivers were more aware of the benefits of caring for a family member diagnosed with dementia than Euro-American caregivers, they were also more likely to indicate perceived stigma and inclination to conceal family members' diagnoses (Vickrey et al., 2007). Inclusion of racially and ethnically diverse individuals in research concerning anticipated ADRD stigma is particularly important given the potential for cumulative effects of stigma as a member of minority group with a dementia diagnosis. Most research examining "double stigma" among racially and ethnically diverse older adults has examined additional stigma of a mental health diagnosis, such as depression (e.g., Sirey et al., 2014). Yet there is evidence to suggest that cultural background influences perceptions of dementia, and minority older adults are less likely to seek help for dementia or do so at later disease stages (see Sayegh & Knight, 2013, for an overview).

Furthermore, well-educated and generally healthy participants (only 7.1% of participants indicated poor self-perceived health) are likely to be representative of healthy aging and may not accurately reflect aging experiences with fewer resources and more health problems. Despite this healthy sample, anticipated ADRD stigma still related to dementia-related anxiety, raising the possibility that the relationship is even stronger among individuals with poorer health and lower education. Alternatively, people with poor health may be less concerned with ADRD because other health challenges are more pressing.

Another limitation is the lack of information about participants' cognitive status. Excluding individuals who did not pass attention checks is believed to have decreased the diversity of cognitive functioning within the sample, excluding those with cognitive decline. However, because exclusion criteria resulted in the rejection of 71.4% of participants who started the study, it is likely that some cognitively intact respondents were also excluded. Future studies would benefit from inclusion of objective cognitive assessment allowing for comparisons of individuals with and without objective impairment. Generally, subjective memory complaint does not predict objective functioning (e.g., Edmonds, Delano-Wood, Galasko, Salmon, & Bondi, 2014); however, it remains unclear how individuals with objective impairment may differ in their anticipated ADRD stigma and dementia-related anxiety. Related to the unexpectedly high exclusion rate, consideration of alternate attention checks may be helpful in future studies. When collecting data online, attention checks presumably increase data quality. However, 335 participants (52.4% of individuals who started the study) failed the second attention check, suggesting it is overly stringent.

Despite these weaknesses, the study does confirm the relationship between anticipated ADRD stigma and dementia-related anxiety among middle-aged and older adults. Based on Patterson and colleagues' review of findings (2018), it is clear that individuals diagnosed with ADRD report experiencing social stigma. Here, we focused on expectation of changes in how family and friends would perceive and treat an individual diagnosed with ADRD, suggesting that greater anticipated social stigma is associated with greater dementia-related anxiety. Given that higher levels of anticipated depression stigma resulted in lower likelihood for receiving mental health referrals (Sirey et al., 2014), similar effects may occur

with ADRD stigma. Future studies could assess interest in neuropsychological testing referrals or preparation for future care, in an effort to understand whether dementia-related stigma and anxiety lead to information seeking versus avoidance regarding objective cognitive functioning or long-term care planning. Future studies may also include the option for information seeking specific to genetic risk for AD with increasing accessibility of genetic testing. Given the contribution of self-perceived ADRD risk in dementia-related anxiety in the present study, an increased understanding of (in)accuracy of self-perceived risk would also be helpful. At present, it is unknown whether objective confirmation of low AD risk results in adjustments of self-perceived ADRD risk and lowered dementia-related anxiety. It will also be important to determine the clinical significance of dementia-related anxiety as well as the overlap and distinction between dementia-related anxiety and other anxiety disorders. Mild to moderate levels of dementia-related anxiety could be adaptive if they motivate healthy lifestyle changes, whereas high levels may lead to avoidance and negative effects on health and daily functioning. More research is needed to examine these possibilities.

Conclusions

Ageist attitudes are prevalent, evident at young ages, and generally sustained (for a review, see North & Fiske, 2012). Given the cognitive focus of negative age-related stereotypes, it is perhaps not surprising that ADRD, a set of disorders associated with cognitive decline and later life, are stigmatized. Relevant to the present results, the many negative perceptions about ADRD contribute to dementia-related anxiety, along with greater self-perceived ADRD risk and poorer self-perceived physical health. Interventions aimed at reducing the stigma associated with aging and ADRD may reduce dementia-related anxiety as well. Indeed, following a supportive intervention from an older adult peer educator, depressed older adults reported lower stigma associated with depression as well as lower depressive symptoms (Connor, McKinnon, Roker, Ward, & Brown, 2018). If these results generalize to other diagnoses, individuals coping with their own ADRD may be uniquely suited to help others reduce stigma and negative attitudes about ADRD and dementia-related anxiety. Given negative perceptions of ADRD at the societal level, Van Gorp and Vercruysse (2012) also suggest creation of, and emphasis on, "counterframes" in media coverage and communication about ADRD (e.g., for the frame of dementia as an "invader" slowly stealing one's identity, a counterframe could be the "strange travelling companion" in which dementia is unexpected and inconvenient but becomes a companion one learns to cope with) creating an opportunity for large-scale change in perceptions of ADRD and reduction in stigmatization.

Acknowledgments

References

Alzheimer's Association. (2018). Alzheimer's disease facts and figures. Alzheimer's and Dementia, 14, 367–429. 10.1016/j.jalz.2018.02.001

Bowen CE, Kessler E-M, & Segler J (2019). Dementia worry in middle-aged and older adults in Germany: Sociodemographic, health-related, and psychological correlates. European Journal of Ageing, 16, 39–52. 10.1007/s10433-018-0462-7 [PubMed: 30886559]

Cohen P (2012). In our prime: The invention of middle age. New York: Scribner.

Connor KO, McKinnon SA, Roker R, Ward CJ, & Brown C (2018). Mitigating the stigma of mental illness among older adults living with depression: The benefit of contact with a peer educator. Stigma and Health, 3, 93–101. 10.1037/sah0000076

Cui R, Maxfield M, & Fiske A (in press). Dementia-related anxiety and coping styles associated with suicidal ideation. Aging & Mental Health. 10.1080/13607863.2019.1636205

Cutler SJ, & Hodgson LG (2001). Correlates of personal concerns about developing Alzheimer's disease among middle-aged persons. American Journal of Alzheimer's Disease and Other Dementias, 16, 335–343. 10.1177/153331750101600604

Edmonds EC, Delano-Wood L, Galasko DR, Salmon DP, & Bondi MW (2014). Subjective cognitive complaints contribute to misdiagnosis of mild cognitive impairment. Journal of the International Neuropsychological Society, 20, 836–847. 10.1017/S135561771400068X [PubMed: 25156329]

French SL, Floyd M, Wilkins S, & Osato S (2012). The Fear of Alzheimer's Disease Scale: A new measure designed to assess anticipatory dementia in older adults. International Journal of Geriatric Psychiatry, 27, 521–528. 10.1002/gps.2747 [PubMed: 21721044]

Fresson M, Dardenne B, Geurten M, & Meulemans T (2017). The effect of stereotype threat on older people's clinical cognitive outcomes: Investigating the moderating role of dementia worry. The Clinical Neuropsychologist, 31, 1306–1328. 10.1080/13854046.2017.1307456 [PubMed: 28349725]

Johnson R, Harkins K, Cary M, Sankar P, & Karlawish J (2015). The relative contributions of disease label and disease prognosis to Alzheimer's stigma: A vignette-based experiment. Social Sciences and Medicine, 143, 117–127. 10.1016/j.socscimed.2015.08.031

Kessler E, Bowen CE, Baer M, Frölich L, & Wahl H (2012). Dementia worry: A psychological examination of an unexplored phenomenon. European Journal of Aging, 9, 275–284. 10.1007/s10433-012-0242-8 [PubMed: 28804427]

Kinzer A, & Suhr JA (2016). Dementia worry and its relationship to dementia exposure, psychological factors, and subjective memory concerns. Applied Neuropsychology: Adult, 23, 196–204. 10.1080/23279095.2015.1030669 [PubMed: 26496236]

Kite ME, Stockdale GD, Whitley BE Jr., & Johnson BT (2005). Attitudes toward younger and older adults: An updated meta-analytic review. Journal of Social Issues, 61, 241–266. 10.1111/j.1540-4560.2005.00404.x

Levenson H (1981). Differentiating among internality, powerful others, and chance. In Lefcourt HM (Ed.), Research with the locus of control construct (Vol. 1, pp. 15–63). New York: Academic Press.

Levy BR (2009). Stereotype embodiment: A psychosocial approach to aging. Current Directions in Psychological Science, 18, 332–336. 10.1111/j.1467-8721.2009.01662.x [PubMed: 20802838]

Maxfield M, Cui R, Roberts JR, & Fiske A (in press). Interest in dementia testing: Understanding the roles of family history, dementia-related anxiety, and coping styles. GeroPsych.

McMurtray AM, Ringman J, Chao SZ, Licht E, Saul RE, & Mendez MF (2006). Family history of dementia in early-onset versus very late-onset Alzheimer's disease. International Journal of Geriatric Psychiatry, 21, 597–598. 10.1002/gps.1540 [PubMed: 16783800]

MetLife Foundation. (2011). What America thinks: MetLife Foundation Alzheimer's survey. Rochester, NY: Harris Interactive.

Molden J, & Maxfield M (2017). The impact of aging stereotypes on dementia worry. European Journal of Aging, 14, 29–37. 10.1007/s10433-016-0378-z [PubMed: 28804392]

North MS, & Fiske ST (2012). An inconvenienced youth? Ageism and its potential intergenerational roots. Psychological Bulletin, 138, 982–997. 10.1037/a0027843 [PubMed: 22448913]

Patterson KM, Clarke C, Wolverson EL, & Moniz-Cook ED (2018). Through the eyes of others – The social experiences of people with dementia: A systematic literature review and synthesis. International Psychogeriatrics, 30, 791–805. 10.1017/S1041610216002374 [PubMed: 29970210]

Raeifar E, Halkett A, Lohman MC, & Sirey JA (2017). The relation between mastery, anticipated stigma and depression among older adults in a primary care setting. The Journal of Nervous and Mental Disease, 205, 801–804. 10.1097/NMD.0000000000000686 [PubMed: 28961595]

Reynolds WM (1982). Development of reliable and valid short forms of the Marlowe-Crowne social desirability scale. Journal of Clinical Psychology, 38, 119–125.

Roberts JR, & Maxfield M (2018). Examining the relationship between religious and spiritual motivation and worry about Alzheimer's disease in later life. Journal of Religion and Health, 57, 2500–2514. 10.1007/s10943-018-0635-x [PubMed: 29730806]

Salthouse TA (2010). Selective review of cognitive aging. Journal of the International Neuropsychological Society, 16, 754–760. [PubMed: 20673381]

Sarkisian CA, Steers WN, Hays RD, & Mangione CM (2005). Development of the 12-item Expectations Regarding Aging survey. The Gerontologist, 45, 240–248. [PubMed: 15799989]

Sayegh P, & Knight BG (2013). Cross-cultural differences in dementia: The Sociocultural Health Belief Model. International Psychogeriatrics, 25, 517–530. [PubMed: 23237243]

Sirey JA, Franklin AJ, McKenzie SE, Ghosh S, & Raue PJ (2014). Race, stigma, and mental health referrals among clients of aging services who screened positive for depression. Psychiatric Services, 65, 537–540. [PubMed: 24687104]

Stites SD, Johnson R, Harkins K, Sankar P, Xie D, & Karlawish J (2018). Identifiable characteristics and potentially malleable beliefs predict stigmatizing attributions toward persons with Alzheimer's disease dementia: Results of a survey of the U.S. general public. Health Communication, 33, 264–271. 10.1080/10410236.2016.1255847 [PubMed: 28033471]

Van Gorp B, & Vercruysse T (2012). Frames and counter-frames giving meaning to dementia: A framing analysis of media content. Social Science & Medicine, 74, 1274–1281. 10.1016/j.socscimed.2011.12.045 [PubMed: 22386639]

Vickrey BG, Strickland TL, Fitten LJ, Adams GR, Ortiz F, & Hays RD (2007). Ethnic variations in dementia caregiving experiences. Journal of Human Behavior in the Social Environment, 15, 233–249. 10.1300/J137v15n02_14

von dem Knesebeck O, Angermeyer MC, Lüdecke D, & Korahl C (2014). Emotional reactions toward people with dementia – results of a population survey from Germany. International Psychogeriatrics, 26, 435–441. 10.1017/S1041610213002056 [PubMed: 24267659]

Werner P (2005). Social distance towards a person with Alzheimer's disease. International Journal of Geriatric Psychiatry, 20, 182–188. 10.1002/gps.1268 [PubMed: 15660404]

Werner P (2014). Stigma and Alzheimer's disease: A systematic review of evidence, theory, and methods. In Corrigan PW (Ed.), The stigma of disease and disability: Understanding causes and overcoming injustices (pp. 223–244). Washington, DC: American Psychological Association.

Yun SW, & Maxfield M (in press). Correlates of dementia-related anxiety: Self-perceived dementia risk and ageism. Educational Gerontology.

Zarit SH, Polenick CA, DePasquale N, Liu Y, & Bangerter LR (2019). Family support and caregiving in middle and late life. In Fiese BH, Celano M, Deater-Deckard K, Jouriles EN, & Whisman MA (Eds.), APA handbook of contemporary family psychology: Applications and broad impact of family psychology (pp. 103–119). Washington, DC: American Psychological Association.

Table 1.

Participant characteristics and group differences based on ADRD exposure

	Possible scale range	Overall sample N = 183 M (SD)	No ADRD exposure N = 66 M (SD)	Nongenetic ADRD exposure N = 55 M (SD)	Genetic ADRD exposure N = 62 M (SD)
Age	40 to 80	59.74 (9.63)	58.02 (9.58)	61.89 (9.36)	59.66 (9.68)
Years of education		14.17 (2.16)	14.06 (2.15)	14.18 (2.26)	14.28 (2.09)
General health	1 to 5	2.86 (.93)	2.86 (1.02)	2.95 (.85)	2.79 (.91)
DWS*	12 to 60	20.94 (9.72)	18.64 (7.50)$_a$	20.33 (8.93)$_a$	23.94 (11.67)$_b$
ACSS	1 to 4	2.40 (.68)	2.27 (.78)	2.40 (.65)	2.54 (.58)
Per risk**	1 to 5	2.54 (.94)	2.21 (.69)$_a$	2.33 (.88)$_a$	3.06 (.99)$_b$
ERA-12	1 to 4	2.41 (.48)	2.37 (.52)	2.51 (.40)	2.35 (.48)
SDS	0 to 13	8.17 (2.82)	8.76 (2.49)	8.11 (2.49)	7.61 (3.30)
Internality	0 to 48	33.67 (6.32)	33.61 (6.75)	34.45 (5.37)	33.05 (6.63)
Powerful others	0 to 48	18.90 (9.19)	19.89 (8.99)	19.15 (8.93)	17.61 (9.63)
Chance	0 to 48	20.05 (8.88)	21.39 (9.17)	19.60 (7.68)	19.02 (9.51)

Note. DWS = Dementia Worry Scale; ACSS = Anticipated Cost of Stigma Scale; Per risk = self-perceived ADRD risk; ERA-12 = Expectations about Aging; SDS = Social Desirability Scale. Numbers with differing subscripts indicate significant group differences.

*
p .01

**
p .001.

Table 2.

Hierarchical regression analysis: association between ACSS and dementia-related anxiety

Block	Predictor	Model 1		Model 2		Model 3	
		B	β	B	β	B	β
Demographics	Age	−.13	−.13	−.13	−.13*	−.11	−.11
	Sex	2.90	.15*	2.00	.10	2.28	.12*
	Years education	−.25	−.36	−.19	−.04	−.15	−.03
	Relationship status	−1.48	−.08	−.67	−.03	−.42	−.02
	General health	−3.69	−.35***	−1.93	−.19**	−1.91	−.18**
ADRD	Self-per risk			5.88	.57***	5.64	.66***
	ADRD exposure			.06	.01	−.19	−.02
Stigma	ACSS					2.25	.16**
R^2			.16		.45		.47
Adjusted R^2			.14		.43		.45
R^2 change			.159***		.291***		.023**

Note. Comparison categories: male = 0, single/divorced/widowed = 0, no ADRD exposure = 0; ADRD = Alzheimer's disease and related disorders; Self-per Risk = self-perceived ADRD risk; ACSS = Anticipated Cost of Stigma Scale.

*
$p < .05$

**
$p < .01$

***
$p < .001$.

Table 3.

Psychosocial correlates of dementia-related anxiety

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
1. DWS	–	.29**	-.30**	.63**	-.35**	-.04	.22*	.25**	.23*	-.34**	-.12	-.13
2. ACSS		–	-.29**	.21*	.24**	.19*	.25**	.15	.17	-.08	-.09	-.04
3. ERA-12			–	-.29**	.23**	.03	-.39**	-.38**	-.02	.40**	.03	.14
4. Per Risk				–	-.17	-.04	.10	.12	.38**	-.29**	.02	-.08
5. SDS					–	.19*	-.18	-.22*	-.17	.16	.29**	-.01
6. Internal						–	-.07	-.14	-.04	.08	.05	-.06
7. Powerful							–	.69**	-.10	-.11	-.03	-.03
8. Chance								–	-.11	-.16	-.14	-.13
9. Exposure									–	-.03	.07	.04
10. Health										–	-.06	.14
11. Age											–	.01
12. Education												–

Note. DWS = Dementia Worry Scale; ACSS = Anticipated Cost of Stigma Scale; ERA-12 = Expectations about Aging; Per Risk = self-perceived ADRD risk; SDS = Social Desirability Scale; Internal = Internal Locus of Control Subscale; Powerful = Powerful Others Locus of Control Subscale; Chance = Chance Locus of control Subscale; Health = subjective report of overall health.

*
p .01

**
p .001.