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Concern about developing Alzheimer's disease or dementia and intention to be screened: An analysis of national survey data

Weizhou Tang[a], **Kristie Kannaley**[a], **Daniela B. Friedman**[a,*], **Valerie J. Edwards**[b], **Sara Wilcox**[a], **Sue E. Levkoff**[a], **Rebecca H. Hunter**[c], **Cheryl Irmiter**[d], and **Basia Belza**[e]

[a]University of South Carolina, Columbia, SC, USA

[b]Centers for Disease Control and Prevention, Atlanta, GA, USA

[c]University of North Carolina, Chapel Hill, NC, USA

[d]Easter Seals Inc., Chicago, IL, USA

[e]University of Washington, Seattle, Washington, USA

Abstract

Objective—Early diagnosis of Alzheimer's disease (AD) or dementia is important so that patients can express treatment preferences, subsequently allowing caregivers to make decisions consistent with their wishes. This study explored the relationship between people's concern about developing AD/dementia, likelihood to be screened/tested, if experiencing changes in cognitive status or functioning, and concerns about sharing the diagnostic information with others.

Method—A descriptive study was conducted using Porter Novelli's SummerStyles 2013 online survey data. Of the 6105 panelists aged 18+ who received the survey, 4033 adults responded (response rate: 66%). Chi squares were used with case-level weighting applied.

Results—Almost 13% of respondents reported being very worried or worried about getting AD/dementia, with women more worried than men ($p < .001$), and AD/dementia caregivers more worried than other types of caregivers ($p = .04$). Women were also more likely than men to agree to be screened/tested if experiencing changes in memory and/or thinking ($p < .001$). The greater the worry, the more likely respondents would agree to be screened/tested ($p < .001$). Nearly 66% of respondents were concerned that sharing a diagnosis would change the way others think/feel about them, with women reporting greater concern than men ($p = .003$).

Conclusion—Findings demonstrate that level of worry about AD/dementia is associated with the reported likelihood that individuals agree to be screened/tested. This information will be useful in developing communication strategies to address public concern about AD/dementia that may increase the likelihood of screening and early detection.

Keywords

Dementia; Alzheimer's disease; Concern; Screening intention; Survey

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[*]Corresponding author at: 915 Greene Street, Room 557, Columbia, SC 29208. dbfriedman@sc.edu (D.B. Friedman).

Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the CDC.

1. Introduction

An estimated 5.4 million Americans have Alzheimer's disease (AD) (Alzheimer's Association, 2016). One in nine of people aged 65 or older has the disease (Alzheimer's Association, 2016; Hebert, Weuve, Scherr, & Evans, 2013). According to a United States survey with over 1000 adults conducted by the MetLife Foundation (2011), 31% of respondents identified AD as their most feared illness when presented with a list of health issues including cancer, AD, stroke, heart disease and diabetes. Perceived susceptibility and perceived severity about developing a disease are central components of health behavior research (Conner & Norman, 2005). Previous studies have explored people's worry about developing AD and other dementias (Cutler, 2015; Cutler & Brăgaru, 2015; Kessler, Bowen, Baer, Froelich, & Wahl, 2012; Kinzer & Suhr, 2016; Roberts, McLaughlin, & Connell, 2014; Werner, 2002; Werner, Goldberg, Mandel, & Korczyn, 2013; Yeo, Horan, Jones, & Pendleton, 2007; Zeng et al., 2015). Some researchers found that participants' worry changed with age (Cutler, 2015; Cutler & Brăgaru, 2015; Roberts et al., 2014), while others found no differences in worry across age groups (Yeo et al., 2007). Additional studies demonstrate that knowing someone with AD (e.g., family members, friends, informal caregivers) is associated with worry about developing the disease (Cutler, 2015; Roberts et al., 2014). Perceived severity of the disease and the belief that one has a poor memory have also been associated with greater worry (Cutler, 2015; Werner, 2002). Although some national and international research has found gender to play a role in worry about developing AD or other dementias, there are discrepancies among these studies, suggesting the need for additional research on people's worry about getting AD or other dementias.

Controversies exist about the risks and value of early detection. There may be potential adverse effects of screening such as the risk of misdiagnosis, emotional impact, time and cost, and possible stigma related to diagnosis (Boustani, Peterson, Hanson, Harris, & Lohr, 2003; Bunn et al., 2012; Iliffe & Manthorpe, 2004). However, benefits of being screened for dementia include being able to receive early treatment (Malouf & Birks, 2004), make shifts from high-cost care (e.g., emergency department, hospital, nursing home) to lower-cost care (e.g., ambulatory care, adult daycare, assisted living) (Borson et al., 2013), and plan and make arrangements (Boustani et al., 2011). There is growing literature on people's willingness to be screened for AD and other dementias (Boustani et al., 2011; Boustani, Watson, Fultz, Perkins, & Druckenbrod, 2003; Fowler et al., 2012; Hurt, Burns, Brown, & Barrowclough, 2012; Holsinger, Boustani, Abbot, & Williams, 2011; Robinson, Canavan, & O'Keeffe, 2014). Preferences for screening and diagnosis may decline when people have the opportunity to consider the consequences of their decision (Robinson et al., 2014). Mixed findings are reported regarding whether gender (Boustani Peterson et al., 2003; Holsinger et al., 2011) or age (Boustani Peterson et al., 2003; Boustani Watson et al., 2003; Fowler et al., 2012; Robinson et al., 2014) influences one's willingness to be screened for AD. Factors such as increased number of medications, having comorbidities, and the presence of hearing or vision problems are associated with increased acceptance of screening (Boustani Peterson et al., 2003; Boustani Watson et al., 2003). In addition, previous studies show a discrepancy regarding care-givers' willingness to accept screening compared with non-caregivers (Boustani et al., 2011; Hurt et al., 2012; Robinson et al., 2014). Currently, there is no cure for AD. Early diagnosis is important so that people who have or potentially may have AD can express preferences for treatment while cognitively able. More information is needed to explore potential influences on people's likelihood to agree to be screened or tested for AD.

The current study examines people's worry about developing AD or dementia, their intention to be screened, and their concerns about sharing the diagnostic information with others using a large, nationally representative sample in the U.S.

2. Methods

2.1. Survey data

We conducted a descriptive study using Porter Novelli's (2013) *SummerStyles* online survey data to examine people's worry about developing AD or dementia as they age, likelihood of agreeing to be screened or tested for the disease, and concerns about sharing the diagnostic information with others. The study was considered exempt by the university Institutional Review Board (IRB). *SummerStyles* is one of three online surveys conducted by Porter Novelli that employs an online research panel (KnowledgePanel®) consisting of 50,000 panelists weighted to be representative of the entire U.S. population (Porter Novelli Public Services, 2013). Responses were weighted by nine factors: gender, age, household income, race/ethnicity, household size, education, census region, metro status, and prior Internet access to match the U.S. Current Population Survey (CPS) proportions (Porter Novelli Public Services, 2013). After data collection, the Centers for Disease Control and Prevention (CDC) licenses the results of this survey from Porter Novelli.

2.2. Survey sampling

Panel members are randomly recruited by probability-based sampling using both random-digit dial and address-based sampling methods, regardless of whether they have landline phones or Internet access. The panel is continuously replenished and maintains approximately 50,000 panelists.

The summer wave (*SummerStyles*) used in this study was conducted from June 28 to July 26, 2013. The survey was sent to a total of 6105 panelists including a random sample of 4497 panelists aged 18 and older, as well as a supplemental sample of 1608 panelists who participated in a previously administered *Styles* survey. (The supplemental sample was included in the fielding of *SummerStyles* in order to collect adult–youth dyad data, however, this data was not applicable to the current study). Respondents who did not answer at least half of the questions were removed from the sample ($n = 79$). A total of 4033 adults completed the entire survey for a final response rate of 66%. The analysis for this current study is based on complete responses to specific questions from 4033 adults.

2.3. Survey questions

We used data from the *SummerStyles* survey to examine people's concern about getting "AD or dementia," likelihood of agreeing to be screened or tested for the disease, and concerns about sharing the diagnostic information with others by asking respondents: (1) "Which one of these conditions are you most afraid of getting, including cancer, Alzheimer’s disease or dementia, stroke, and others?”; (2) “How worried are you about getting Alzheimer’s disease or dementia as you get older?”; (3) “If you were experiencing changes in memory and/or thinking ability, how likely is it that you would agree to be screened or tested for Alzheimer’s disease or dementia?”; (4) “If you were diagnosed with Alzheimer’s disease or dementia, how concerned would you be that sharing this information with others would change the way they think and feel about you?”; and (5) “What is the primary reason you would be concerned about sharing this information?” A 5-point Likert scale was used for the first four questions in the survey, with “1” being “very worried/likely/concerned,” “4” being “not at all,” and “5” being “don’t know.” For the fifth question, response options were provided including, “Family/friends would treat me differently,” and “I would be left out of social activities.” Survey questions and response options can be found in Appendix A.

Caregiving status and care recipient condition were assessed with the following questions: “During the past month, did you provide any such care or assistance to a friend or family member?” and “What has the doctor said is the major health problem that the person you care for has?” The responses of participants who indicated that they were providing care to someone with AD/ dementia were compared with those of caregivers of persons with any other condition.

We analyzed the data using SPSS version 19.0 (IBM Statistics for Windows, Version 19.0. Armonk, New York). Weighted estimates and 95% confidence intervals were examined. The analyses were repeated to compare caregivers of people with AD, caregivers for persons with other types of health conditions, and non-caregivers. Associations between variables were examined with chi-square tests. Comparison between general caregivers and non-caregivers on the association between respondents’ level of worry and their likelihood of agreeing to be screened or tested was examined using logistic regression analysis. All tests were calculated at $p < .05$. All analyses were performed with case-level weighting applied.

3. Results

3.1. Respondent characteristics

Among the total 4033 respondents in the sample, over half were women (weighted estimate, 51.8%; 95% confidence interval [95% CI], 49.5–54.0%), with an average age of 46.5 years (SD = 17.2, range 18–91). More than three quarters (78.7%) reported their race as white, 53.5% were married, and more than half had some college (27.2%) or a bachelor’s degree or higher (28.2%). The majority of respondents rated their general health as good (38.9%), very good (35.7%), or excellent (10.0%). Among all respondents, 14.4% were caregivers who provided regular care or assistance to a friend or family member with a health problem or disability; 11.6% were caregivers of persons with AD/dementia versus 80.9% who identified as caregivers of persons with other diseases, including heart disease or stroke (14.8%), cancer (12.4%), diabetes (7.4%), chronic obstructive pulmonary disease (6.0%), and other conditions (results not shown in table).

3.2. Fear and worry about getting AD or dementia

Fear of getting AD/dementia—When asked "Which one of these conditions are you most afraid of getting," cancer was feared most among the respondents (40.3%). There were 17.5% of respondents who were most afraid of getting AD/dementia compared with diseases such as stroke (11.4%), HIV (5.1%), diabetes (3.1%), and depression (1.4%). Among those who were most afraid of getting AD/dementia, 62.6% were women. Almost two thirds of people most afraid about getting AD/dementia reported having at least some college (63.5%) and were above age 45 (63.2%). Chi-square tests revealed significant gender differences with more women (41.5%) than men (39.0%) being most afraid of getting cancer, more women (21.2%) than men (13.6%) being most afraid of getting AD/ dementia, but more men than women being most afraid of getting all other types of diseases including stroke, depression, diabetes, and so on (p <.001). There were also significant differences among age groups for those who were most afraid of getting AD/dementia. A higher percentage of older respondents chose AD/dementia, with 22.7% of respondents aged 60+, 18.9% aged 45–59, 14.4% aged 30–44, and 13.2% aged 18–29 (p <.001). Among the 829 respondents most afraid of getting AD/dementia, 15.4% were caregivers, within which 26.0% were caregivers for a person with AD/dementia. There were no significant differences in most feared condition among types of caregivers (p =.16) (results not shown in table).

Worry about getting AD/dementia—Participants were also asked, "How worried are you about getting Alzheimer's disease or dementia as you get older?" 12.8% of respondents were very worried or worried about getting AD/dementia, 41.9% were somewhat worried, and 35.4% were not worried at all. Chi-square tests revealed that people who were most afraid of getting AD/ dementia were more likely to be worried about getting AD/ dementia than those who were afraid of getting other diseases (stroke, cancer, HIV, etc.) and those who were not afraid of getting any disease (p <.001; Table 1). Gender, age, and caregiver status were significantly associated with respondent's level of worry (Table 2). Women were significantly more worried about getting AD/dementia than men (p <.001). Adults who were above 45 years old were also more worried about getting AD/dementia compared to younger adults, especially those aged 45–59 years (15.5% vs. 12.8% aged 30–44 and 11.4% aged 18–29; p <.001). Caregivers were more worried than non-caregivers, with 18.4% of caregivers very worried or worried compared to 11.9% of non-caregivers, and 44.3% of caregivers were somewhat worried compared to 41.5% of non-caregivers (p = .004). Besides, among caregivers of persons with AD/dementia, 23.5% were very worried or worried about getting AD/dementia, and 53.3% felt somewhat worried. Caregivers of persons with AD/dementia were significantly more worried about getting AD/dementia than caregivers for people with other health conditions (p = .035; Table 3).

3.3. Perceived likelihood of agreeing to be screened or tested for AD or dementia

Almost half of the sample (47.1%) agreed that they would be likely or very likely to get screened or tested for AD/dementia if they were experiencing changes in memory and/or thinking ability. Almost one third (30.4%) of respondents indicated they were "somewhat likely," and 11.9% of respondents were not likely to be screened for AD/dementia. Likelihood of agreeing to be screened or tested differed by gender, with women being significantly more likely to report screening intentions compared with men (p <.001; Table

2). Likelihood of agreeing to be screened or tested also differed by age group, with respondents aged 60+ reporting that they would be likely or very likely to report screening intentions compared with younger adults (50.8% vs. 48.0% aged 45–59, 46.0% aged 30–44, and 42.9% aged 18–29; $p = .011$).

Furthermore, there were 359 caregivers (54.8% vs. 45.9% of non-caregivers) very likely or likely to agree to be screened or tested for AD/dementia if they were experiencing changes in memory and/or thinking ability (73 of the total 546 were specifically AD/dementia caregivers), and fewer caregivers (11.2%) than non-caregivers (12.0%) reported they were not at all likely to be screened or tested. There were significant differences between caregivers and non-caregivers in regard to their likelihood of agreeing to be screened or tested ($p = .005$). However, there were no significant differences between caregivers of persons with AD/dementia and caregivers of people with other health conditions ($p = .08$; Table 3).

The data support a relationship between respondents' level of worry and their likelihood of agreeing to be screened or tested. Among those 556 individuals who were very worried or worried about getting AD/dementia, 74.8% were very likely or likely to be screened or tested ($p <.001$). We also examined whether being a caregiver would moderate the relationship between respondents' level of worry and their likelihood to be screened or tested. A logistic regression analysis with an interaction term (being a caregiver × level of worry) was conducted. The association between respondents' level of worry and their likelihood of agreeing to be screened or tested was not found to differ significantly between caregivers and non-caregivers ($p = .911$).

3.4. Concerns about sharing AD or dementia diagnostic information

Respondents' concerns about sharing diagnostic information with others if they were diagnosed with AD/dementia were examined. More than half of respondents were very concerned or concerned (30.8%), or somewhat concerned (35.1%) that sharing their disease diagnosis with others would change the way others think and feel about them. When asked about the primary reason why they would be concerned about sharing information, 54.2% of respondents were concerned that their family and friends would treat them differently, 20.3% were concerned that they would be talked to differently, and 6.6% were worried about giving up driving. Other reasons included "I would be left out of social activities" (4.8%), "I would lose control over my finances" (4.5%) and other reasons not listed (9.7%). Women were more concerned about sharing their diagnostic information with others than men ($p = .003$; Table 2), with 33.9% of women versus 27.6% of men who were very concerned or concerned, and fewer women (20.9%) than men (26.0%) were not concerned at all. However, the reasons why individuals would be concerned about sharing diagnostic information did not differ by gender ($p = .42$). We found a significant relationship between concern of sharing the diagnosis and level of worry about getting AD/dementia, wherein people who were more worried about getting AD would be more concerned about sharing their diagnosis with others ($p <.001$).

Almost half of caregivers of people with AD/dementia (49.3%) were very concerned/ concerned about sharing diagnostic information, while only 33.4% of caregivers of persons with other conditions were concerned at the same level. However, there were no significant differences between these two groups regarding their level of concern with sharing an AD/dementia diagnosis with others ($p = .25$; Table 3).

4. Discussion

This study contributes new knowledge regarding people's concern about getting AD/dementia, including their fear and worry, their willingness to be screened or tested for AD/dementia if experiencing changes in memory and/or thinking, and their concerns about sharing the diagnostic information with others. Consistent with results from several studies (Cutler, 2015; Cutler & Hodgson, 2001; Werner et al., 2013), our findings suggest that women are more worried about getting AD/dementia than men. As noted earlier, this contrasts with results from some other studies (Cutler & Brăgaru, 2015; Kinzer & Suhr, 2016) that did not find gender to be a significant factor in such worry. We also found that age was associated with individuals' worry about getting AD/ dementia, with adults aged 45 and older being more concerned about getting AD compared with younger adults, which is consistent with previous findings (Cutler, 2015; Roberts et al., 2014).

Furthermore, results demonstrated that caregivers were more worried about getting AD/dementia than non-caregivers. There are several possible reasons for this. Cutler and Brăgaru (2015) found that 65.4% of survey respondents identified family history of the disease as a risk factor to developing AD. Individuals who have family members with the disease may be more educated about its origins and genetic connections. Additionally, the experience of caregiving may heighten the reality of the disease and highlight the struggles of individuals who suffer from it, thus bringing about a greater level of worry. Because our results also showed that caregivers of persons with AD/dementia are more worried about getting AD/dementia than caregivers of people with other diseases, it is possible that the level of worry is heightened by personal experience with the disease.

The current study also showed that overall level of worry was associated with the likelihood that individuals would agree to be screened or tested for AD/dementia. This finding is consistent with findings from research on breast cancer demonstrating that worry about breast cancer may motivate screening behaviors (Hay, McCaul, & Magnan, 2006). Early diagnosis and screening for AD/ dementia is important even though there is no cure for the disease. The World Alzheimer's Report (2011) listed several benefits of early diagnosis, such as allowing people to plan ahead while having the capacity to make decisions, increasing access to available interventions which may improve their cognitive functioning, and delaying institutionalization that may help enhance the quality of life for both patients and caregivers.

Overall, both men and women expressed a substantial level of concern that sharing a potential diagnosis of AD/dementia would change the way others think and feel about them. Most common reasons found in this study included concerns related to stigma, i.e., that family or friends would treat them differently, or they would be talked to differently. These concerns may emerge due to negative stereotypes (Blay & Peluso, 2010; Phillipson, Magee, Jones, Reis, & Skaldzien, 2015), misinformation about the disease (Blay & Peluso, 2008), and a fear of being viewed as dependent or needing to be institutionalized (Iliffe et al., 2005). Current research on stereotypes has provided some insight into the effectiveness of educational strategies for reducing the stigma associated with mental illness (Kelly, Jorm, & Wright, 2007; Henderson & Thornicroft, 2009; Vaughan & Hansen, 2004). Therefore, it is important to decrease stereotypical beliefs and promote a wider acceptance of individuals with this diagnosis through AD educational campaigns.

This study has limitations. Our data came from a cross-sectional survey, and causality cannot be inferred from the results. The information was self-reported, and thus respondents' actual perceptions and behaviors may differ from self-reports. Also, there is a limitation with the content of the actual questions included in the survey. The response categories provided to the participants limited their options and may have influenced their answers. Nonetheless, our findings are meaningful in understanding people's concern about getting AD/dementia, their likelihood of agreeing to be screened or tested, and their concerns about sharing a potential diagnosis of the disease.

Future research should consider the magnitude of the associations found within this study in order to determine the extent to which these factors (gender, age, perceived stigmatization, caregiver status, etc.) influence worry about getting AD or dementia and willingness to be screened. Interactions among individual factors may significantly affect the level of worry experienced by an individual. This information could be useful for the development of communication strategies to address people's concerns that may increase the likelihood of screening and early detection.

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Appendix A. Survey questions

Which one of these conditions are you most afraid of getting?

1. Alzheimer’s disease or dementia
2. Cancer
3. Depression
4. Diabetes
5. Human Immunodefficiency Virus (HIV)
6. Stroke
7. Not afraid of getting any of these

How worried are you about getting dementia or Alzheimer’s disease as you get older?

1. Very worried
2. Worried
3. Somewhat worried
4. Not at all worried
5. Don’t know

If you were experiencing changes in memory and/or thinking ability, how likely is it that you would agree to be screened or tested for dementia or Alzheimer’s disease?

1. Very likely

2. Likely
3. Somewhat likely
4. Not at all likely
5. Don't know

If you were diagnosed with dementia or Alzheimer's disease, how concerned would you be that sharing this information with others would change the way they think and feel about you?

1. Very concerned
2. Concerned
3. Somewhat concerned
4. Not at all concerned
5. Don't know

What is the primary reason you would be concerned about sharing this information?

1. Family/friends would treat me differently
2. I would be left out of social activities
3. I would be talked to differently
4. I would have to give up driving
5. I would lose control over my finances
6. Other reason not listed

People may provide regular care or assistance to a friend or family member who has a health problem or disability. During the past month, did you provide any such care or assistance to a friend or family member?

1. Yes
2. No

What has the doctor said is the major health problem that the person you care for has?

1. Cancer
2. Chronic obstructive pulmonary disease
3. Diabetes
4. Alzheimer's disease or dementia
5. Heart disease or stroke
6. Other
7. Don't know

In general, would you say your health is . . . ?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

Table 1

Level of worry by fear of getting AD/dementia or other conditions, Porter Novelli 2013 SummerStyles Survey Data (N = 4033)[a]

Variable	**Afraid of getting AD/dementia**[b]	**Afraid of getting other conditions**[b]	**Not afraid of getting any of the conditions**[b]
	N **(%)**	***N*** **(%)**	***N*** **(%)**
Level of worry[c]			
Very worried or worried	249 (27.0)	291 (12.7)	14 (1.2)
Somewhat worried	472 (58.1)	1188 (45.4)	167 (18.7)
Not at all worried	80 (10.4)	724 (33.3)	495 (62.3)
Don't know	28 (4.4)	181 (8.6)	105 (17.8)

[a] Data from the SummerStyles survey were weighted by gender, age, household income, race/ethnicity, household size, education, census region, metro status, and prior Internet access.

[b] Percentages are % within "afraid of getting AD/dementia", "afraid of getting other conditions", and "not afraid of getting any of the conditions".

[c] $\chi^2 = 738.26$, df = 6, $p < .001$.

Table 2

Worry, likelihood of agreeing to be screened/tested, and concerns about sharing diagnostic information by gender, age, and caregiver status, Porter Novelli 2013 SummerStyles Survey Data ($N = 4033$)[a]

Variable	**Gender**[b]		**Age**[b]				**Caregiver status**[b]	
	Women	**Men**	**18–29**	**30–44**	**45–59**	**60+**	**Caregiver**	**Non-caregiver**
Level of worry[c]	***N* (%)**		***N* (%)**				***N* (%)**	
Very worried or worried	337 (15.0)	219 (10.5)	64 (11.4)	156 (30.8)	200 (45.7)	65 (12.1)	113 (18.4)	443 (11.9)
Somewhat worried	1005 (45.3)	831 (38.2)	127 (12.8)	389 (38.5)	306 (36.8)	85 (11.8)	308 (44.3)	1524 (41.5)
Not at all worried	599 (30.1)	706 (41.1)	208 (15.5)	621 (43.1)	449 (32.1)	102 (9.3)	178 (29.9)	1121 (36.2)
Don't know	164 (9.6)	155 (10.1)	157 (11.0)	670 (52.9)	350 (29.4)	67 (6.7)	47 (7.4)	271 (10.3)
Likelihood of agreeing to be screened/tested[d]								
Very likely or likely	1100 (52.0)	874 (41.9)	211 (42.9)	450 (46.0)	690 (48.0)	623 (50.8)	359 (54.8)	1612 (45.9)
Somewhat likely	655 (27.8)	641 (33.2)	140 (28.3)	276 (29.4)	438 (31.6)	442 (31.9)	187 (28.3)	1106 (30.8)
Not at all likely	181 (10.4)	222 (13.6)	62 (13.3)	96 (13.0)	141 (11.1)	104 (10.7)	58 (11.2)	343 (12.0)
Don't know	174 (9.8)	170 (11.3)	73 (15.5)	87 (11.7)	109 (9.3)	75 (6.6)	42 (5.7)	299 (11.3)
Concerns about sharing diagnostic information[e]								
Very concerned or concerned	757 (33.9)	573 (27.6)	161 (29.7)	326 (34.5)	505 (33.8)	338 (24.6)	240 (34.3)	1088 (30.3)
Somewhat concerned	763 (35.9)	686 (34.2)	171 (35.5)	308 (32.7)	467 (32.3)	503 (40.3)	220 (36.3)	1226 (34.9)
Not at all concerned	427 (20.9)	488 (26.0)	95 (21.6)	176 (20.5)	318 (24.6)	326 (26.4)	147 (22.4)	763 (23.5)
Don't know	152 (9.3)	160 (12.2)	54 (13.3)	96 (12.2)	88 (9.2)	74 (8.7)	38 (7.0)	273 (11.3)

[a] Data from the SummerStyles survey were weighted by gender, age, household income, race/ethnicity, household size, education, census region, metro status, and prior Internet access.

[b] Percentages are % within gender, age, and caregiver status.

[c] Gender: $\chi^2 = 61.99$, df = 3, $p < .001$; age: $\chi^2 = 124.93$, df = 9, $p < .001$; caregiver status: $\chi^2 = 26.79$, df = 3, $p = .004$.

[d] Gender: $\chi^2 = 42.29$, df = 3, $p < .001$; age: $\chi^2 = 50.19$, df = 9, $p = .011$; caregiver status: $\chi^2 = 24.39$, df = 3, $p = .005$.

[e] Gender: $\chi^2 = 32.77$, df = 3, $p = .003$; age: $\chi^2 = 55.59$, df = 9, $p = .005$; caregiver status: $\chi^2 = 11.43$, df = 3, $p > .05$.

Table 3

Caregivers' worry, likelihood of agreeing to be screened/tested, and concerns about sharing diagnostic information, Porter Novelli 2013 SummerStyles Survey Data ($N = 650$)[a]

Variable	**AD/dementia caregivers**	**Other disease caregivers**	**Caregivers don't know condition of care recipient**
	***N* (%)**[b]	***N* (%)**[b]	***N* (%)**[b]
Level of worry[c]			
Very worried or worried	21 (23.5)	88 (19.2)	4 (3.0)
Somewhat worried	42 (53.3)	246 (43.5)	17 (37.6)
Not at all worried	17 (20.6)	149 (30.2)	11 (42.4)
Don't know	3 (2.6)	35 (7.1)	8 (17.0)
Likelihood of agreeing to be screened/tested[d]			
Very likely or likely	55 (61.0)	284 (54.8)	18 (44.2)
Somewhat likely	18 (25.0)	163 (29.9)	5 (17.1)
Not at all likely	7 (12.2)	42 (10.0)	7 (21.6)
Don't know	3 (1.8)	29 (5.3)	10 (17.1)
Concerns about sharing diagnostic information[e]			
Very concerned or concerned	37 (49.3)	188 (33.4)	13 (20.9)
Somewhat concerned	24 (30.0)	181 (36.0)	13 (47.2)
Not at all concerned	17 (13.7)	122 (24.1)	7 (18.7)
Don't know	4 (7.0)	27 (6.5)	7 (13.2)

[a] Data from the SummerStyles survey were weighted by gender, age, household income, race/ethnicity, household size, education, census region, metro status, and prior Internet access.

[b] Percentages are % within condition type.

[c] $\chi^2 = 22.24$, df = 6, $p = .035$.

[d] $\chi^2 = 22.48$, df = 6, $p > .05$.

[e] $\chi^2 = 16.11$, df = 6, $p > .05$.