Archives of Gerontology and Geriatrics 71 (2017) 43–49

Contents lists available at ScienceDirect

Archives of Gerontology and Geriatrics

journal homepage: www.elsevier.com/locate/archger

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

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ARTICLE INFO

Article history:
Received 24 October 2016
Received in revised form 23 December 2016
Accepted 25 February 2017
Available online 1 March 2017

Keywords:
Dementia
Alzheimer's disease
Concern
Screening intention
Survey

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.

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

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http://dx.doi.org/10.1016/j.archger.2017.02.013
0167-4943/

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 caregivers' 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.