Correlates of personal concerns about developing Alzheimer's disease among middle-aged persons

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Abstract

We examine correlates of personal concerns about developing Alzheimer's disease (AD) among (1) adult children, 40 to 60 years of age, who have a living parent with a diagnosis of probable AD (N = 108), and (2) a matched comparison group of persons with no parental history of AD (N = 150). Using stepwise regression, predictors measuring subjective perceptions of memory functioning, overall family history of AD, knowledge of AD, and sociodemographic characteristics were entered into models for the total sample and each of the subsamples. The results indicate that worries about memory functioning play a consistent role in personal concerns about developing AD across both groups, but that additional pathways to personal concerns differ among individuals having and not having a parent with AD.

Key words: Alzheimer's disease, familial Alzheimer's disease, perceptions, preclinical signs and symptoms, predictors

> I once spent two days looking for my keys, convinced I was stricken with early-onset dementia, only to find them in the corner of a closet.
>
> David L. Wheeler,
> "A Quarrel with his Son Prompts
> a Writer to Meditate on Hope,"
> *Chronicle of Higher Education*,
> October 2, 1998: B2.

> It is not me currently with Alzheimer's disease. But any time I misuse a word, forget a name I have and should have known, momentarily lose the car in a parking lot, I scare the bergeebers out of me! I fear becoming a victim of AD, and then my dearest of husbands would be left alone. I come to dripping tears thinking of this possibility. I fear for his future.
>
> *Alzheimer's Digest*, July 29, 1999.

Introduction

Cognitive lapses are a common experience for those in the middle and later years. For some people, the occurrence of a memory problem may evoke a passing reference to dementia in general or to Alzheimer's disease (AD) in particular. In these instances, dementia is little more than a quick and convenient explanation for a memory problem, but one that is neither taken very seriously nor of much real concern. However, for other persons, age-associated episodes of forgetting in everyday situations can result in significant personal concerns and worries about the development of AD.[1] In turn, such anxieties may have a detrimental effect on psychological and physical well-being.[2,3]

In previous pilot work, we have referred to this phenomenon as "anticipatory dementia," that is, the fear among middle-aged persons that cognitive lapses may be an early warning signal or a harbinger of the onset of AD. Preliminary analyses showed that personal concerns about the development of Alzheimer's were indeed associated with the frequency and severity of self-reported memory problems. Understandably, middle-aged children who had a living parent with AD were more likely to express concerns than persons from a matched sample of individuals with no parental history of AD. However, the relationship between self-reported memory problems and personal concerns was evident in each

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of the subsamples.[4] The connection between cognitive problems and AD has apparently gained such visibility that this symptom is seen to be the most common marker of the disease.

A major thrust of current behavioral and biomedical research on AD is to disentangle “benign” memory lapses that occur in middle age from similarly expressed cognitive problems with a trajectory actually resulting in AD.[5-8] If such research does eventually lead to the capacity to distinguish normal from pathological cognitive problems, it would represent a significant diagnostic achievement, especially since treatment efficacy is partially a function of early detection. However, in the absence of a nearly definitive diagnosis, psychosocial and cultural factors will likely play a role in illness attribution; personal concerns about developing AD are subject to individual interpretation and to social construction.[9,10] If persons perceive the root cause of cognitive impairments to be the early stages of dementia, the concern is real regardless of whether the attribution is correct or incorrect. As W.I. Thomas said a number of years ago, “If [people] perceive a situation as real, it is real in its consequences.”[11]

In this study, we focus on psychosocial and other precursors of personal concerns about developing AD. By using a sample comprising adult children with a living parent who has a diagnosis of probable AD and a comparison group with no parental history of dementia, we examine the correlates of personal concerns for the sample as a whole and for each of the subsamples. Personal concerns are placed in the predictive contexts of memory functioning self-assessments, knowledge of and exposure to AD, and sociodemographic characteristics of respondents.

On the basis of earlier work,[3,4,12,13] we expect that concerns will be greater among the adult children, but personal concerns about developing AD will be linked to self-assessments of memory functioning in both subsamples. Persons who are more knowledgeable about and familiar with AD should have higher levels of concern, as should women and those who are married. Women tend to monitor their health more closely than men and are more open in acknowledging health concerns.[14,15] Heightened concern among the married might reflect possible caregiving burdens that would be imposed on one’s spouse. Because the prevalence of AD increases with age, older respondents are expected to be more concerned. Finally, we are less certain about the effects of education. Persons with higher levels of education may be more cognizant of the tenuous relationship between cognitive lapses in middle age and the onset of AD, and therefore may be less concerned. Alternatively, if education is a surrogate for socioeconomic status and economic resources, higher levels of education may evoke greater concern due to the potential impact of AD on a family’s resource base.

Methods

Design

The sampling design for this study called for two groups of respondents: (a) adult children, between the ages of 40 and 60, with a living parent having a diagnosis of probable AD, and (b) a matched comparison group of men and women with no parental history of the disease. A number of organizations located in the Northeast—including Alzheimer’s Association chapters, hospital-based clinics, and community facilities—assisted in recruitment of the 108 adult children. The subsample of adult children is purposive and self-selected; respondents signaled their willingness to participate in the research by returning an informed consent card or calling a toll-free number. For the comparison group, a random sample of 150 men and women in three communities was selected. The three communities were chosen because they were the hometowns of the preponderance of the persons in the adult children sample, and in this way both subsamples were more likely to have similar demographic profiles. Data were collected via telephone interviews by the New England Research Institutes between September 1999 and August 2000, and lasted an average of 34 minutes (39 minutes for the adult children and 31 for the comparison group).

Sample

Characteristics of the sample are presented in Table 1. Overall, the sample is largely female, white, Catholic, married, employed full-time, and well educated. Sixty-six percent of the respondents are women and 95 percent are white. For the sample as a whole, the average age is 49.7. When the profiles of the two subsamples are compared, the only statistically significant difference is in gender: 25 percent of the adult children are males as opposed to 41 percent of the comparison group ($\chi^2 = 6.86$, df = 1, $p < .01$). Given the random selection of the comparison group versus the self-selection of the adult children and because females are more likely to be in the types of primary or secondary caregiving roles where they would be exposed to our recruitment solicitations, this difference is not surprising. Statistical controls will be employed as appropriate to take this gender disparity into account.

Measures

The dependent variable for this analysis is a single-item measure based on the following question asked of

Table 1. Sample characteristics

	Total	Adult children	Comparison group
Gender: %			
Female	65.9	75.0	59.3
Male	34.1	25.0	40.7
Race: %			
White	95.3	95.4	95.3
Nonwhite	4.7	4.6	4.7
Religion: %			
Protestant	27.6	28.7	26.8
Catholic	45.1	41.7	47.7
Jewish	9.7	13.0	7.4
Other	8.6	10.2	7.4
None	8.9	6.5	10.7
Marital status: %			
Married	76.0	71.3	79.3
Widowed	2.3	1.9	2.7
Divorced	11.2	13.9	9.3
Separated	2.3	2.8	2.0
Never married	8.1	10.2	6.7
Work status: %			
Full-time	67.4	64.8	69.3
Part-time	16.7	15.7	17.3
Not working	15.9	19.4	13.3
Years of education: mean (SD)	15.4 (2.1)	15.4 (2.0)	15.3 (2.1)
Age: mean (SD)	49.7 (5.6)	50.0 (5.6)	49.4 (5.6)
N	258	108	150

Note: Differences between the two subsamples were statistically significant for gender ($p < .01$) and statistically insignificant for all other variables.

all respondents: "I would like to ask how concerned *you* are about personally developing Alzheimer's disease. Would you say you are *very* concerned, *somewhat* concerned, *not very* concerned, or *not at all* concerned about developing Alzheimer's?" For the total sample, 24.0 percent indicated they were "very" concerned (coded 1), 41.5 percent responded that they were "somewhat" concerned (coded 2), 22.1 percent said they were "not very" concerned (coded 3), and 12.4 percent were "not at all" concerned (coded 4).

Several predictors are used in the analysis, which for convenience may be placed in three groups. First, subjective assessments of memory functioning were measured with a variety of indicators. Respondents were asked how they would rate their memory at the present time ("excellent" = 1, 15.5 percent; "very good" = 2, 43.0 percent; "good" = 3, 31.4 percent; "fair" = 4, 8.1 percent; "poor" = 5; 1.9 percent) and whether they thought their memory had changed in recent years ("no" = 1, 26.3 percent; "yes" = 2, 73.7 percent). They were also asked if anyone has mentioned noticing changes in their memory ("no" = 1, 84.5 percent; "yes" = 2; 15.5 percent) and whether their ability to remember causes them any worry ("no" = 1, 66.3 percent; "yes" = 2, 33.7 percent). Finally, we included a 12-item subset of the Short Inventory of Memory Experiences (SIME),[16] which asks about everyday experiences of remembering and forgetting (*e.g.*, "How often do you find that just when you want to introduce someone you know to someone else, you cannot think of their name?"). For each item, seven-point response categories are used, with scores ranging from "never" (coded 7) to "always" (coded 1). Scores were summed and divided by the number of valid responses, yielding an average score for each respondent (range = 3.00-6.83, mean = 5.44, standard deviation [SD] = .69, Chronbach's alpha = .79).

Second, we measured knowledge of and exposure to AD. Our measure of knowledge is based on an eight-item battery asking whether each statement about AD (*e.g.*, "Alzheimer's disease is a normal part of aging") is true or false. The number of correct responses (with "don't knows" and "refusals" considered as incorrect) was summed (range: 2-8; mean = 5.95; SD = 1.48). Exposure to AD was measured by summing (to a maximum of four) the number of family member respondents indicated as having had AD (0 = 39.9 percent; 1 = 38.0 percent; 2 = 13.2 percent; 3 = 5.8 percent; 4 = 3.1 percent).

Finally, sociodemographic predictors included level of educational attainment (coded in years of education), age (coded in years), gender (male = 1; female = 2), marital status (married = 1; not married = 2), and whether the respondent was a member of the adult children subsample (coded 1) or the comparison group (coded 2). Distributional characteristics of this last set of variables are given in Table 1.

Analysis

We present the results of the analysis in two stages. The data in Table 2 give the bivariate correlation coefficients between personal concerns about developing AD and the predictors for both the total sample and each of the subsamples. Since many of the predictors are themselves correlated, we then present the results of a series of stepwise regression analyses, again for both the total sample and each of the subsamples, to identify predictors that are significantly and independently associated with personal concerns respondents have about developing AD. To determine whether the processes operating within the subsamples are the same or different, we also note results from between-sample comparisons of the unstandardized regression coefficients β for each predictor.[17]

Results

The data in Table 2 present the bivariate correlation coefficients between respondents' personal concerns about developing AD and the predictor variables. For the total sample, personal concerns are associated with several of the variables measuring self-reports of memory functioning. Respondents who report that their memory has changed, whose ability to remember causes them to be worried, and whose scores on the SIME indicate more frequent memory problems in everyday situations are all more concerned about the possibility of developing AD. Greater knowledge of AD and the number of family members with the disease also predict personal concerns. Of the sociodemographic variables, gender emerges as a significant predictor, with females being more concerned. However, the strongest predictor is sample membership. Not surprisingly, adult children with a living parent who has been diagnosed as having probable AD are more likely to be concerned than are members of the comparison group, where there is no parental history of AD. To put a different quantitative face on it, 92 percent of the adult children are either "very" or "somewhat" concerned about developing AD as compared with 47 percent of the comparison group.

Although the specific constellation varies, subjective perceptions of memory functioning are associated with higher levels of concern in both of the subsamples: self-rated memory functioning and being worried about one's memory among the adult children; and having experienced memory changes, being worried about one's memory, and more frequent problems with everyday

Table 2. Correlations between personal concerns about developing Alzheimer's and predictor variables

	Total sample	Adult children	Comparison group
Memory rating	-.092	-.195*	-.087
Memory change	-.160*	-.106	-.180*
Others noticed change	-.035	-.093	-.008
Memory worry	-.378***	-.360**	-.313***
SIME	.169**	.014	.294***
AD knowledge	-.356***	-.131	-.258**
AD family exposure	-.358***	-.046	-.125
Education	-.025	-.217*	.079
Age	-.038	.005	-.023
Gender	-.265***	-.181	-.233**
Marital status	.084	.183	.135
Sample	.493***	—	—

* p < .05; ** p < .01; *** p < .001

memory as measured by the SIME among the comparison group. Education is the only other significant predictor for the adult children, with greater concerns being related to higher levels of educational attainment. For the comparison group, greater knowledge of AD and being female are associated with higher levels of concern.

Stepwise regression analyses were conducted to identify sets of unique and significant predictors for the total sample and for each of the subsamples. The results of these analyses are presented in Table 3.

For the total sample, five significant predictors emerge. Personal concerns are greater among the adult children than among the comparison group, if persons are worried about their memory, if they are women, if they are married, and with increasing knowledge about AD. Together, this set of variables explains 36 percent of the variance in personal concerns. Variables that were significant in the bivariate analysis that emerge as nonsignificant in the regression analysis include whether persons believe their memory has changed, having experienced more frequent everyday memory problems, and the number of family members who have been diagnosed with AD.

For the adult children, only two predictors emerge as significant. Those who are worried about their memory are more concerned about developing AD, as are those who have higher levels of educational attainment. These two variables account for 14 percent of the variance. How one rates one's memory, significant at the bivariate level, is not among the significant predictors in the regression analysis.

Our measure of personal concerns about developing AD is significantly related to four predictors among the comparison group. Once again, being worried about one's memory is the strongest predictor, but self-reports of having experienced more everyday memory problems and being more informed about AD are also robust predictors. Interestingly, higher levels of education are associated with *lower* levels of concern among persons with no

Table 3. Regression coefficients for the relationships between personal concerns about developing Alzheimer's and predictor variables

	Standardized β		
	Total sample	Adult children	Comparison group
Memory rating	-.015	-.094	.168
Memory change	-.020	.072	-.051
Others noticed change	.013	.009	.090
Memory worry	-.259***	-.338***	-.238**
SIME	.104	-.075	.218**
AD knowledge	-.126*	-.071	-.235**
AD family exposure	-.032	-.038	-.045
Education	.056	-.186*	.202**
Age	.002	-.032	-.011
Gender	-.145**	-.124	-.130
Marital status	.105*	.124	.132
Sample	.376***	—	—
Adjusted R^2	.360	.144	.193
(N)	(255)	(106)	(149)

* p < .05; ** p < .01; *** p < .001

parental history of AD, whereas more education was associated with *greater* concern in the adult children. As a set, these four variables explain 19 percent of the variance in concerns about developing AD in the comparison group. Whether one's memory has changed in recent years drops out from the set of significant predictors.

Finally, analysis of the unstandardized coefficients (not shown in Table 3) underscores both the similarities and differences in the processes operating within each of the subsamples. For example, the difference between the coefficients on the variable measuring whether respondents worry about their memory is nonsignificant ($t = 0.37$, $df = 253$, ns), indicating that the effects of worrying on personal concerns about developing AD are the same in each of the subsamples. On the other hand, the effects of the SIME ($t = 3.04$, $df = 253$, $p < .001$) and education ($t = 3.02$, $df = 253$, $p < .001$) differ significantly between the two subsamples. All other tests for differences in the β coefficients are nonsignificant.

Discussion

AD has emerged as a major threat to the well-being of middle-aged and older persons and their families. Rarely invoked as a diagnosis a quarter century ago and little known among the lay population, AD is now almost universally recognized for the progressive deterioration of cognitive functioning and physical health it causes. Also widely known are the early symptoms, which most often take the form of problems with cognitive functioning. Yet memory lapses and other cognitive problems are not necessarily precursors of dementia. Nevertheless, due to the visibility AD has attained, it is not surprising that people link changes in memory functioning to the possible onset or early manifestations of the disease. Because these anxieties may themselves be detrimental to well-being,[2,3] it is important to identify circumstances conducive to the emergence of personal concerns people may have about whether Alzheimer's is in their future.

Building on an earlier pilot study, this research has examined correlates of personal concerns about developing AD. Because of the nature of our sample, we are able to look at correlates among middle-aged persons who have a living parent with AD and a matched, comparison group for whom there is no parental history of the disease. Thus, we can compare persons whose family history causes them to be intimately familiar with the onset and progression of the disease with persons who are more representative of the lay population and for whom knowledge of AD is likely to be more cursory and impressionistic.

The results of the regression analysis show first the powerful influence of having a parent with AD. This first-hand exposure, perhaps coupled with the knowledge that genetic risk is higher among first-degree relatives,[18,19] leads the adult children to be far more personally concerned about developing the disease than are members of the comparison group. As Green notes, "Adult children of parents with AD see in their parents a possible future for themselves..."[20]

A precursor of concerns about developing AD that is common to both groups is whether one's ability to remember causes any worry. That worrying about one's memory is the strongest predictor in each of the subsamples provides further evidence of the close connection people make between memory functioning and AD. Given that objective assessments of cognitive performance are imperfectly correlated with self-reports of cognitive functioning,[21-24] these findings also underscore the importance of subjective perceptions in the anticipatory dementia process. Whether the worries are justified or not, if people report that their ability to remember causes them to worry, they are also more likely to have concerns about developing AD. This linkage appears to be equally applicable to middle-aged persons who have a parent with AD and to their counterparts who have no parental history of the disease. Further confirmation of the role that subjective assessments of cognitive functioning play in determining who is likely to be concerned about developing AD is found in the significant effect of the SIME in the comparison group. Even in the absence of a parental history of AD, persons reporting more frequent problems with everyday memory have higher levels of concern. Thus, both sets of findings lend additional support to the existence of the phenomenon we have labeled as anticipatory dementia—*i.e.*, the way in which subjective interpretations of memory functioning affect personal concerns and anxieties about developing AD—and to the contention that this process occurs regardless of whether there is a family history of AD.[4]

Greater knowledge of AD is associated with having concerns, but primarily in the comparison group. It may be that the adult children are very knowledgeable to begin with and there is less variance here. In fact, the mean number of correct responses for the adult children is 6.6 (out of eight) in contrast to 5.5 for the comparison group ($F = 37.23$, $df = 1$, $p < .001$), and the variance is smaller (1.3 versus 2.4). For the comparison group, knowing more about AD may draw further attention to the role of cognition in the early stages and to the fact that AD does not just run in families. Paradoxically, by increasing awareness of symptoms and susceptibility, greater knowledge may heighten concern.

Gender and marital status are significant predictors for the total sample. Women express greater concerns than men, a finding which is consistent with other research on gender differences in the illness process.[14,15] That persons who are married are more concerned than the unmarried is perhaps a reflection of the projected burdens of caregiving on spouses.[25] However, neither predictor is significant when the subsamples are examined separately, and this likely reflects the smaller number of cases for the subgroup analyses.

The effects of education vary, depending on whether one is an adult child or a member of the comparison group. For the adult children, personal concerns about developing AD increase as level of educational attainment rises. For those in the comparison group, concerns decrease the higher the level of educational attainment. Why these relationships run in opposite directions is not immediately apparent. One explanation may have to do with the degree to which educational attainment is connected to the sophistication of the respondent's understanding of AD. Highly educated individuals may be aware that familial AD is associated with early onset of the disease. Then, adult children, who have the familial connection, may see themselves as entirely vulnerable to the disease, even in middle age. In contrast, the comparison group, who have no evidence of a familial link, know that sporadic AD is more likely to occur in old age, and therefore do not see themselves as especially vulnerable. These explanations are merely speculative, and the processes underlying the countervailing effects of education merit further consideration.

While this study clearly supports the hypothesis that subjective assessments of memory functioning play a role in the existence of concerns and anxieties about developing AD, the research also has limitations that need to be acknowledged. For one, a larger sample would have had more power to detect significant differences, particularly in subgroup analyses. The sample is also drawn primarily from metropolitan areas and from one geographic region. Consistent with what other studies have found, recruitment of minorities proved to be difficult.[13,26] As Table 1 indicates, our study is no exception in that members of minority groups are under-represented in the sample. Both in terms of location and composition, a more representative sample would be valuable.

In retrospect, early design decisions limiting eligibility among adult children to those 40 to 60 years of age and with a *living* parent with AD were perhaps unnecessarily restrictive. Sample recruitment, already a challenge for this population,[27] was made more difficult with these criteria in place. As an alternative, both a wider age range and whether the parent was living or deceased could be treated as variables in the analysis.

Our analysis of personal concerns about developing AD was based on a single item. Although this measure appears to have both face and predictive validity, it would be useful to assess personal concerns in greater depth. Indicators such as how frequently persons worry about developing AD, their subjective evaluation of its likelihood, and when they believe they will develop AD would have been valuable measures in addition to the extent of personal concerns.[13]

In the interests of comparability, the same set of predictors was used in the subgroup analyses of the adult children and the comparison group. Yet a variety of measures more specific to the situation of AD are available for the adult children. For instance, we have variables indicating whether the parent and child are of the same gender or different genders; we know how different in age respondents are from the age when symptoms were first noticed in their parents;[28] and we have measures of how similar the specific cognitive lapses being experienced by the respondent are to those evidenced by the parent in the early stages of the disease. Subsequent analyses of concerns about developing AD that focus exclusively on the adult children will take advantage of the availability of this more extensive set of predictors. This is all the more important given that only two variables emerged here as significant correlates of concerns among the adult children.

Conclusion

We have learned from this study that adult children who have a living parent with AD are more concerned about developing the disease themselves than are middle-aged persons having no parental history of the disease. However, for both groups, personal concerns about developing AD are associated with subjective assessments of memory functioning. Further analyses will also examine the effects of both subjective assessments of cognitive functioning and concerns about developing AD on a variety of outcomes. For instance, we expect that these factors will have implications for the process of symptom seeking[29-31] and whether persons engage in help-seeking behaviors.[32]

More generally, we believe these additional analyses will shed light on the pathways and processes by which anticipatory dementia may lead to the early detection of AD, the possibility of more effective treatment, and a greater likelihood of active involvement by the afflicted individual in decisions relevant to the course of the disease.

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