This exploratory study examines the link between memory appraisals and personal concerns about developing Alzheimer's disease. The sample of persons ages 40–60 includes adult children with a living parent who has Alzheimer's disease (N = 25) and a matched group with no family history of dementia (N = 25). Using two composite measures of memory appraisals, the results show significant bivariate and multivariate relationships between self-assessments of memory functioning and concerns about developing the disease. The findings also suggest that negative memory appraisals evoke concerns about developing Alzheimer's disease within both of the subsamples.

Key Words: Metamemory, Memory functioning, Dementia anxiety, Age-associated memory change

Anticipatory Dementia: A Link Between Memory Appraisals and Concerns About Developing Alzheimer’s Disease

Stephen J. Cutler, PhD and Lynne Gershenson Hodgson, PhD

If I can’t think of a word, if I forget who someone is, if I go downstairs and say “now, what did I come down here for?” I wonder, am I getting Alzheimer’s? Has Alzheimer’s started?

— 47-year-old daughter of a mother with Alzheimer’s disease

These words from one of our respondents point to a previously unstudied phenomenon: the concern of the children of Alzheimer’s disease patients that their own normal age-associated memory change is a harbinger of dementia, a concern that their parent’s disease will become their own. And this worry may not necessarily be confined to family members of persons with Alzheimer’s disease. Those in the general population may voice similar concerns about age-associated memory change being an early warning signal of cognitive impairment in their future. We refer to this phenomenon as “anticipatory dementia.” Its existence has been corroborated by first-person accounts written by relatives of persons with Alzheimer’s disease (e.g., Konek, 1991), and some attention has been given to this general set of issues in the case of other diseases with a genetic basis (e.g., Hunt & Walker, 1991 regarding Huntington’s disease and Siebert, 1995 in the case of hypertrophic cardiomyopathy), but there have been no systematic investigations in the area of Alzheimer’s disease.

Numerous studies, of course, have examined the nature of age differences and age changes in cognitive functioning (Hultsch & Dixon, 1990; Nebes & Madden, 1988). Of particular relevance is the consistent finding that objective performance on memory tests, subjective appraisals of memory functioning, and concerns about memory problems are associated with age (Cavanaugh, Grady, & Perlmutter, 1983; Erber, Szuchman, & Rothberg, 1992; Fingersman & Perlmutter, 1994; Perlmutter, 1995; Sluss, Gruenberg, Reedman, & Rabins, 1983; West, Crook, & Barron, 1992; Zelinski, Gilewski, & Anthony-Bergstone, 1990). On virtually all indicators, younger persons perform better on memory tasks, report fewer occurrences of memory impairments, and are less concerned about memory failures than middle-aged and older persons (Crook et al., 1986). Although the diagnostic utility of terms such as “benign senescent forgetfulness” and “age-associated memory impairment” (Crook & Larrabee, 1988) is being debated (Deary, 1995; Smith et al., 1991), these and similar labels have been proposed to describe the common, normal memory problems experienced at the middle and older ages.

At the same time, public awareness and recognition of Alzheimer’s disease as an entity affecting large numbers of older persons has increased appreciably over the past two decades. The success of both private foundations and public agencies in educating the population about the characteristic symptoms and progression of the disease, its heightened priority as a research topic within the biomedical, social, and behavioral research communities, and growing media attention to the disease have all led to its steadily
increasing visibility (Fox, 1989). Indeed, results from national surveys conducted in 1985 by N. Cutler (1987) and in 1992 by the Gallup Organization (Alzheimer’s Association, 1993) find a very high level of awareness of the disease among the adult population.

The specific focus of this study is on how personal concerns about the development of Alzheimer’s disease may be linked to subjective perceptions of normal age-associated memory changes. With widespread public awareness, the general hypothesis guiding the study is that common memory problems, perhaps once attributed to normal aging and evoking generalized concerns about memory, may now be interpreted as insidious markers of the onset of Alzheimer’s disease or other dementias.

In addition to the general question of whether normal memory change produces concerns about the onset of Alzheimer’s disease, we also explore whether there are conditions under which ascriptions of incipient dementia are more or less likely to occur. For instance, investigations into the etiology of Alzheimer’s disease point to the presence of a genetic factor (Post, 1994; Whitehouse, 1987). While the precise mechanisms by which this occurs and the extent to which a genetic component is operative are still the subjects of continuing research and debate (Gatz, Lowe, Berg, Mortimer, & Pedersen, 1994), the potentially heightened susceptibility of family members to Alzheimer’s disease provides the basis for two hypotheses: (a) the link between memory appraisals and personal concerns about developing Alzheimer’s disease will vary as a function of the degree of familiarity and personal experience with the disease; that is, negative memory appraisals are more likely to evoke concerns about developing Alzheimer’s disease among adult children with a living parent who has the disease than among persons for whom there is no family history of dementia, and (b) among adult children of persons with Alzheimer’s disease, negative memory appraisals are more likely to evoke concerns about developing the disease when it is believed that it is inheritable.

We also examine whether other factors condition the relationship between memory appraisals and concerns about developing Alzheimer’s disease. For example, anticipatory dementia may be associated with marital status. Given the presence of their spouses as potential caregivers, married persons may be less concerned about developing the disease than unmarried persons. Additionally, unmarried persons who have to rely on their own employment may view the potential of cognitive impairment as being more threatening to their financial security. Therefore, we expect that concerns about developing Alzheimer’s disease will be less dependent on memory appraisals among the married than among the unmarried. Also, theoretical discussions (Verbrugge, 1985) of psychosocial aspects of gender differences in health behavior and in symptom perceptions and reporting lead us to anticipate that the relationship between memory appraisals and concerns about developing Alzheimer’s disease will be stronger for women than for men.

Similarly, we expect to find that the link between concerns about developing Alzheimer’s disease and memory appraisals varies with occupational status and age. We anticipate that the link will be stronger among persons who work in professional, white collar, and in other occupations that require higher levels of cognitive functioning than among persons in blue collar and manual occupations whose employment requires lower levels of cognitive functioning. Age should also condition the relationship between memory appraisals and concerns about developing Alzheimer’s disease because of its increasing incidence at older ages. More generally, examination of the role that such social factors play in moderating the relationship between memory appraisal and concerns about developing Alzheimer’s disease is in keeping with Craik, Byrd, and Swanson’s (1987) plea that “theories of cognitive performance must model the interactions between mental processes and relevant aspects of the environment” (p. 85; see also Task Force on Aging Research, 1995).

Methods

Sample

The sampling design for this exploratory study called for two groups of respondents: (a) adult children, between the ages of 40 and 60, with a living parent with a diagnosis of probable Alzheimer’s disease or other dementia, and (b) a matched control group of men and women with no family history of the disease. Two community organizations serving families of people with Alzheimer’s disease and one nursing home designed specifically for people with dementia assisted with the recruitment of the sample of 25 children with a parent with Alzheimer’s disease. The 25 control group respondents, matched on a variety of social structural characteristics, were recruited from the friendship networks of the original respondents. Interviews, combining a structured questionnaire with elements of a focused interview, were conducted in the homes of the respondents and averaged 47 minutes in length.

The profile of the entire sample presented in Table 1 reveals that it is predominantly female, white, married, Catholic, well educated, and employed full- or part-time. The average age of the respondents is 45. When the profiles of the two subsamples — the 25 adult children of parents with Alzheimer’s disease and the 25 control group respondents — are compared, there are no statistically significant differences on any of the background characteristics, indicating that the two samples are matched demographically.

Measures

Our measure of concern about developing Alzheimer’s disease is based on a single item asked of all respondents: “I’d like to ask how concerned you are about personally developing Alzheimer’s disease. Would you say you’re very concerned, somewhat concerned, not very concerned, or not at all
concerned about developing Alzheimer's?" In response to the question, 10% of the sample indicated they were very concerned (coded 1), 44% were somewhat concerned (coded 2), 32% were not very concerned (coded 3), and 14% were not at all concerned (coded 4).

Subjective appraisals of memory functioning were indexed in two ways. The first measure is the Short Inventory of Memory Experiences (SIME) developed by Herrmann (1979, 1984). It is based on a set of 24 items asking about memory experiences in a variety of everyday situations. Each item is measured on a seven-point scale, with scores ranging from (1) "always" to (7) "never," with higher scores indicating more favorable assessments of memory functioning. For the respondents in this sample, the reliability coefficient (Cronbach's alpha) for the SIME is .878, the mean is 123.7 (range = 24–168, SD = 17.46), and the difference between the two subsamples is non-significant (t = .93, df = 47).

The second measure of memory functioning is based on six questions developed for this study: four closed-ended items asking whether respondents think their memory has changed in recent years, whether others have noticed memory changes, whether the respondent's ability to remember causes any worry, and whether respondents have ever spoken to anyone about their memory; and two open-ended questions probing overall evaluations of memory and feelings about the respondent's ability to remember. Scores on each of the six items were dichotomized and summed, resulting in a composite Memory Assessment Index (MAI) with a possible range of scores from 0 to 6 (mean = 3.76, SD = 1.59, α = .805). Again, higher scores indicate a more positive assessment of memory, and the difference between the two subsamples was non-significant (t = 1.07, df = 48). The correlation between the SIME and the MAI is .615 (p < .001).

Several other variables are used in the analysis. Respondents who make up the control group are coded 0 while the adult children with parents who have Alzheimer's disease are coded 1. Sex is coded 0 for males and 1 for females. Marital status is coded 0 for married respondents and 1 for all others. Age is entered as an interval-level variable. Occupational prestige is measured by the National Opinion Research Center's General Social Survey prestige scores for 1980 U.S. Census occupational codes (Davis & Smith, 1993). Scores range from 19 (lowest prestige) to 86 (highest prestige). The mean prestige score for respondents in the sample is 49.39 (SD = 13.27). Finally, as a measure of beliefs in the inheritability of Alzheimer's disease, respondents were asked (as part of a 10-item knowledge of Alzheimer's battery) whether "Alzheimer's disease can be a hereditary disease, that is, it can run in families and be passed down from one generation to the next." Sixty-four percent of the respondents indicated this statement was true (coded 1) and 36% replied either that it was false or they did not know (coded 0).

Although not used in the analysis, it is worth noting here that all respondents were administered the 6-item Orientation-Concentration-Memory Test (Albert, 1994; Katzman et al., 1983) as a screen for the possible presence of dementia. The mean number of weighted errors for the total sample was 2.38 (possible range = 0–28), and the difference between the adult children of parents with Alzheimer's disease (mean = 2.48) and the control group (mean = 2.28) was not significant (t = 1.30, df = 48). Eighty-eight percent of the respondents in both samples had weighted error scores of 4 or lower, and none of the respondents in either sample had a weighted error score of greater than 10, which would be consistent with the presence of dementia.

### Analysis

Bivariate relationships are examined using Pearson correlation coefficients and multivariate relationships with hierarchical multiple regression analysis. Because a basic question posed in the study is whether the association between memory appraisals and concerns about developing Alzheimer's disease varies between the subsamples and along dimen-
sions of structural and demographic variables, relevant interaction effects are also introduced into the equations. In these cases, the independent variables are entered first, followed by the 2-way interaction terms, then by the 3-way interactions.

Results

We begin by looking at the relationships between personal concerns about developing Alzheimer's disease and the two measures of memory appraisal. Consistent with the basic hypothesis of the study, assessments of memory functioning are clearly related to concerns about developing Alzheimer's disease. For the total sample, the correlation between scores on the Short Inventory of Memory Experiences (SIME) and concerns about developing the disease is .265 (p < .05), while the correlation between scores on the Memory Assessment Index (MAI) and concerns about developing the disease is .358 (p < .01). Both of these relationships indicate that persons who have more negative assessments of their memory functioning are more concerned with personally developing Alzheimer's disease.

The data also show, not surprisingly, that there are sample differences in concerns about developing the disease (r = -.257, p < .05): adult children with living parents who have Alzheimer's disease are more concerned than are the control group respondents, for whom there is no family history of dementia.

Using hierarchical OLS regression procedures, the data in Table 2 present the multivariate relationships between personal concerns about developing Alzheimer's disease, subsample membership, the measures of memory appraisal, and terms for the interactions between subsample membership and the memory appraisal measures. As per our main hypothesis, the results show that both measures of memory appraisal continue to be significant predictors of concerns about developing the disease. Subsample differences in concerns about developing Alzheimer's disease are statistically nonsignificant (p = .13 in the case of the equation including the MAI and p = .054 for the equation containing the SIME).

Of particular interest here, and in contrast to one of our main hypotheses, the interaction effects between subsample membership and the measures of memory appraisal are not significant. This finding suggests that the effects of memory appraisals on personal concerns about developing Alzheimer's disease are constant across the two subsamples.

The data in Table 3 present the results of a series of regression analyses examining the effects of several theoretically relevant variables. In each case, the predictor variable and the measure of memory appraisal are entered first, followed by 2-way interaction effects, and then by the 3-way interaction effect. The final equations presented in Table 3 include only the significant interaction effects. In the absence of significant 2-way interaction effects between subsample membership and memory appraisals (see Table 2), terms for this interaction were not entered into the equations in the interest of efficiency. (As a safeguard, a series of analyses, parallel to those in Table 3, were conducted with the inclusion of 2-way interaction terms between subsample membership and memory appraisal. In only one of the 10 equations was this interaction term significant.) Discussion of these findings is most profitably organized first around the effects of the measures of memory appraisal on personal concerns about developing Alzheimer's disease, then around the effects of the several predictors, and then around the significant interaction effects.

Main Effects

The results of the analyses provide continuing support for our basic hypothesis that personal concerns about developing Alzheimer's disease are associated with memory appraisals. In all of the equations, the more negative the appraisal of one's memory, the greater the concern. These relationships are statistically significant at the .05 level or higher in seven of the 10 equations and at p < .10 in the remaining three. Given the relatively small sample size in the study, the consistency and significance of these relationships provides compelling evidence for a link between concerns about one's susceptibility to Alzheimer's disease and self-assessments of memory functioning.

Of the five predictors — sex, marital status, age, occupational prestige, and beliefs about inheritability — included in the equations, only marital status, age, and occupational prestige are found to be independently related to concerns about developing the disease. The main effects of sex and whether one believes Alzheimer's disease is inheritable are not significant. In the case of marital status, the relationship is significant only for the equation including the SIME, and the direction of the relationship indicates

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Notes: SIME = 24-item Short Inventory of Memory Experiences; MAI = 6-item Memory Assessment Index.

*p < .05.

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that unmarried persons are less concerned about developing Alzheimer’s disease. For both equations, concern is significantly related to age, with older respondents among this group of middle-aged persons showing less concern. The effect of occupational prestige is significant in the case of the equation including the MAI, with the direction of the relationship indicating that concern is greater at the higher levels of occupational prestige.

Two-Way Interaction Effects. — The data in Table 3 show that there are significant 2-way interaction effects between subsample membership and several of the predictors. These effects, apparently obscured in the analysis of the main effects when only the total sample is considered, are directionally consistent with our initial expectations. The significant negative interaction effect between subsample membership and sex in both equations indicates that females with a living parent with Alzheimer’s disease are more concerned about developing the disease themselves. For both sets of equations, there is also a significant interaction effect between subsample membership and marital status. Here, it is unmarried persons who have a parent with Alzheimer’s disease who are more concerned that they themselves might become a victim of the disease.

In contrast to the significant main effect of age, in which increasing age is associated with less concern, the interaction effect between subsample membership and age shows that personal concern about developing Alzheimer’s disease increases with advancing age among the adult children with a parent who has the disease. Among the adult children of persons with Alzheimer’s disease, greater concern is also associated with higher occupational prestige. In these two instances, the significant 2-way interaction effects occur only in the case of the equations including the SIME and the MAI, the interaction effect between subsample membership and beliefs in the inheritability of Alzheimer’s disease is significant: adult children with a parent with Alzheimer’s disease who believe the disease is inheritable are more concerned about developing the disease themselves.

Three-Way Interaction Effects. — Finally, the analyses point to the presence of two significant 3-way interaction effects: MAI × Age × Sample and MAI × PRESTIGE × Sample. In the case of age, and contrary to what we expected, it is the older adult children who appraise their memory more favorably who are more concerned about developing Alzheimer’s disease. For occupational prestige, it is the
combination of being an adult child, having a higher prestige occupation, and again having a more favorable self-assessment of memory functioning that leads to greater personal concerns about developing the disease.

Discussion

The primary objective of this exploratory study was to examine a concept we have labeled “anticipatory dementia.” In particular, we were interested in determining whether there is a connection between the ways in which middle-aged persons appraise their memory functioning and their personal concerns about developing Alzheimer’s disease. The findings, based on a sample of adult children with a living parent with a diagnosis of probable Alzheimer’s disease and a matched sample of persons with no family history of the disease, provided clear and consistent evidence for a relationship between self-evaluations of memory functioning and personal concerns about developing Alzheimer’s disease. Using Herrmann’s (1979) Short Inventory of Memory Experiences (SIME) and the Memory Assessment Index (MAI), which was constructed for this study, we found significant relationships between the extent of personal concern about developing Alzheimer’s disease and memory appraisals: negative assessments of memory functioning were associated with greater concern about developing the disease. Importantly, this relationship occurred both at the bivariate level and in multivariate analyses.

Although sample differences in concerns about developing Alzheimer’s disease were consistent with the results of an earlier study (Cutler, 1987; cf. Price, Shanahan, Price, & Desmond, 1986), our expectation that the relationship between self-evaluations of memory functioning and personal concerns about developing the disease would be more evident among the adult children of Alzheimer’s disease victims was not supported. Interaction terms measuring the joint effects of subsample membership and memory appraisal on concerns about developing Alzheimer’s disease were almost invariably nonsignificant. This finding suggests that memory problems and changes in memory functioning evoke concerns about developing Alzheimer’s regardless of whether one is a member of a family where dementia is present. Of course, our sample is small, of arguable representativeness, and the control group was drawn from the friendship networks of the adult children. If, however, this finding should be replicated on a larger and more representative sample, it would indicate that the phenomenon of anticipatory dementia cuts across the population of middle-aged persons. Upon further reflection, this would not be completely unexpected, given that memory impairments in particular and cognitive dysfunction in general are the most visible, salient, and widely recognized symptoms of the disease. Men and women in the general population who experience memory declines in middle age may make the connection between their own cognitive changes and the most identifiable warning signal of Alzheimer’s disease.

The analyses of the main effects of the other predictors and their interactions with subsample membership and the measures of memory appraisal yielded a more complicated set of findings. Among the adult children, personal concerns about developing Alzheimer’s disease were greater for females, for the unmarried, and for those who believe that Alzheimer’s disease is inheritable. These findings are consistent with our expectations. The gender difference is in agreement with other work suggesting that women are more sensitive to symptoms than men and are more likely to express health-related concerns (Verbrugge, 1985). It may also reflect the fact that adult daughters are more likely to be directly involved in caregiving (Dwyer & Coward, 1991). That unmarried children with a living parent with Alzheimer’s disease are more concerned about developing the disease perhaps can be explained by their worries about the availability of caregiving and support systems should they actually develop the disease. It should also be noted, however, that gender and marital status are confounded in this sample: 93% of the males are married compared with 57% of the females ($x^2 = 6.32, df = 1, p < .05$). To disentangle these effects and to determine whether one of these relationships is spurious will require a larger sample than is presently available. Finally, it is not surprising that concerns about developing Alzheimer’s disease are associated with beliefs about the inheritability of the disease only among the group that is genetically susceptible to it.

Contrary to our initial hypothesis that concern would rise with greater age-related risk of getting the disease, the significant main effect of age suggested that it was the younger persons among this middle-aged group of respondents who were more likely to be concerned about developing Alzheimer’s disease. The interaction effects, however, were somewhat more consistent with our expectations. Here, the results showed that increasing age was associated with greater concern among the adult children, although in the case of the equation including the MAI, concern was greater among the older adult children with more positive appraisals of their memory functioning. Likewise, we generally found that greater concern was associated with holding higher prestige occupations, supporting our original contention that the possibility of developing dementia would be more threatening among persons in more cognitively-based occupational positions. There was some indication that this relationship was more pronounced among the adult children in the case of the equation including the SIME and, again, among the adult children with more positive memory appraisals in the case of the MAI.

Overall, then, the results of this exploratory study point to the utility of the concept of anticipatory dementia in that the memory appraisals of middle-aged persons do appear to play a role in their concerns about developing Alzheimer’s disease. While there are clear limitations on our ability to generalize from this small sample, there are strong indications that this link between self-assessments of memory
functioning and concerns about developing dementia is not restricted to adult children of Alzheimer’s disease victims. The study also demonstrates that concerns about developing Alzheimer’s disease are associated with variables such as sex, marital status, age, occupation, and beliefs about the inheritability of the disease, but that the effects of these factors appear to vary according to whether an immediate family member is afflicted with the disease. Confirmation of these findings, however, must await the results of replications based on larger, more diverse, and more representative samples.

From another perspective, further exploration of the phenomenon of anticipatory dementia might ultimately prove to be of value in educating caregivers, relatives, and others about one specific concern that may arise in connection with Alzheimer’s disease. The literature is rich in studies of caregiver burden, depression, and related outcomes along with implications for educational and supportive interventions to reduce these negative consequences (Gatz, Bengtson, & Blum, 1990; Light & Lebowitz, 1989). We propose that anticipatory dementia may represent another potential threat to psychological well-being and, in our subsequent work, we intend to examine a variety of possible consequences with which it may be associated. To illustrate, there is a well-established relationship between memory appraisal and depression (e.g., Kahn, Zarit, Hilbert, & Niederehe, 1975; La Rue, Swan, & Carmelli, 1995; Lichtenberg, Ross, Millis, & Manning, 1995; O’Hara, Hinrichs, Kohout, Wallace, & Lemke, 1986; Rabbitt, Donlan, Watson, McInnes, & Bent, 1995). Thus, it would be of some interest to determine whether levels of depressive symptomatology differ among persons with similar levels of memory complaints but who vary in their concern about developing Alzheimer’s disease. Similarly, do help-seeking behaviors and everyday functioning differ according to whether memory changes are viewed as part of normal aging or as pathological changes perceived to be early symptoms of the onset of Alzheimer’s disease or related dementias? If anticipatory dementia does, indeed, prove to be detrimental to psychological well-being, a better understanding of the phenomenon would be called for in order to mitigate its negative consequences.

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