Personality Change Precedes Clinical Diagnosis of Dementia of the Alzheimer Type

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We examined personality changes reported by a collateral source on the Blessed Dementia Scale in people who were nondemented when they entered a longitudinal study. Of the 108 participants examined here, 68 received a clinical diagnosis of dementia at some point after entry into the study. The other 40 participants died and came to autopsy with a clinical diagnosis of no dementia; however, 14 received a neuropathological diagnosis of Alzheimer's disease. The results indicate that initial personality changes often occur early, even earlier than clinical diagnosis. Individuals without a clinical diagnosis who showed presence of the disease at autopsy experienced personality changes comparable with those of individuals who had received a clinical diagnosis. Personality changes may aid in the early detection of dementia of the Alzheimer type, which could facilitate early treatment.

EARLY diagnosis of dementia of the Alzheimer type (DAT) gives patients and families more time to plan for the progressive decline that accompanies the disease. It will also enable early implementation of effective interventions when they become available. One way researchers have tried to improve early detection is by analyzing noncognitive symptoms such as behavioral and personality changes that may occur early in the course of the disease (Oppenheim, 1994; Wild, Kaye, & Oken, 1994). The existing research has focused on what changes occur after diagnosis and how these changes are related to the progression of the disease. One approach has been to use the five-factor model of personality (Costa & McCrae, 1992). Retrospective reports by informants indicate that personality changes in DAT commonly include increased neuroticism and decreased extroversion, openness, and conscientiousness (Siegler, Dawson, & Welsh, 1994; Strauss, Pasupathi, & Chatterjee, 1993). Other studies using the five-factor model generally confirm these findings with slight variations (Chatterjee, Strauss, Smyth, & Whitehouse, 1992; Glosser et al., 1995; Welleford, Harkins, & Taylor, 1995; Wild et al., 1994). A second approach has been to use items from the Blessed Dementia Scale (Blessed, Tomlinson, & Roth, 1968), which queries an informant about changes in the individual's personality, drives, and interests. These studies show that demented individuals are frequently rigid and self-centered, lack concern for others, and display coarsening of affect (Bozola, Gorelick, & Freels, 1992; Rubin, Morris, Storandt, & Berg, 1987). Comparable differences have been reported by researchers using the Brooks and McKinlay (1983) Personality Inventory, a series of 18 adjective pairs that was designed for use with people who experienced head injury (Aitken, Simpson, & Burns, 1999; Heinik, Keren, Vainer-Benaiah, Lahav, & Bleich, 1999; Petry, Cummings, Hill, & Shapiro, 1988). As a group, these studies document personality change during the course of DAT, although they rely on retrospective design to track these changes, a method that reveals systematic biases in personality perception (Strauss, Stuckey, Pasupathi, & Moore, 1997).

Although a number of researchers have called for longitudinal studies (e.g., Mychack, Rosen, & Miller, 2001; Siegler et al., 1994), to our knowledge only three previous studies have used longitudinal designs. Two (Petry, Cummings, Hill, & Shapiro, 1989; Rubin et al., 1987) examined personality changes longitudinally after clinical diagnosis. One prospective population-based study (Smith-Gamble et al., 2002) stated that informant-reported personality changes in undiagnosed people predicted dementia status at 2-year follow-up. This was a clinical diagnosis of DAT, not autopsy-confirmed Alzheimer’s disease (AD).

As far as we know, no study has determined at what point personality first changes in persons with DAT and whether such changes may be used to enhance accurate early clinical diagnosis. A more comprehensive research design would include annual assessments of personality among nondemented individuals who eventually develop the disease and those who do not. If personality begins to change early, perhaps even before the emergence of detectable cognitive impairments, then personality changes may be markers that clinicians can use for early disease detection. In the present study we take advantage of data from a longitudinal study to evaluate when personality changes occur for the first time in individuals who develop DAT.

METHODS

Participants

The data that we report on here were collected from 108 nondemented individuals who were recruited to participate in longitudinal studies of healthy aging and dementia between October 29, 1979, and January 25, 2001, and usually were evaluated annually. Of these, 68 (41% men) received a clinical diagnosis of dementia at a subsequent assessment after entry into the study. This group, labeled converters, had 5 to 20 years of
education ($M = 13.7$) and ranged in age from 62 to 100 years ($M = 79.5$) at the last time of evaluation prior to conversion. The individuals in this group were followed for an average of 3.68 years ($SD = 4.14$) before clinical diagnosis. The other 40 participants (50% men) died and came to autopsy with a clinical diagnosis of no dementia; however, 14 (35%) received a neuropathological diagnosis of Alzheimer’s disease (AD; McKeel et al., 1993; National Institute on Aging, 1997). This group is labeled preclinical. They had 8 to 19 years of education ($M = 14.4$), ranged in age from 64 to 93 years ($M = 85.1$) at the time of death, and were followed for an average of 7.97 years ($SD = 5.61$). The remaining 26 who were clinically and neuropathologically nondemented at death had 6 to 20 years of education ($M = 12.9$), ranged in age from 70 to 95 years ($M = 84.6$) at the time of death, and were followed for an average of 4.12 years ($SD = 4.69$). The preclinical and nondemented groups did not differ at their last assessment on any of the measures in a battery of cognitive tests (Galvin et al., 2004). Other data from many of these participants have appeared in numerous publications from the center. The project was approved by the university’s institutional review board.

At annual follow-up, clinicians assessed each older adult for the presence and severity of dementia by using the Clinical Dementia Rating (CDR; Morris, 1993), which is based on a 90-min semistructured interview with the research participant and a knowledgeable collateral source (usually a spouse or adult child), followed by a neurological examination of the participant. The clinician, usually a different person from year to year, was unaware of the results of previous clinical evaluations or of previous or current psychometric test results. The diagnosis of DAT with a CDR of 0.5 or greater was based on a history of gradual onset and progressive cognitive impairment and was comparable with that specified in the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (American Psychiatric Association, 1994). Diagnostic accuracy for AD as verified by postmortem examination in 207 individuals was 93% (Berg et al., 1998). The converter group also contained 7 individuals who received a diagnosis of uncertain dementia. Although they had a CDR of 0.5 (very mild impairment), the clinician was not sure if the impairment was due to DAT. A previous study (Morris et al., 2001) reported that individuals who died and came to autopsy with this clinical diagnosis had a neuropathological diagnosis of AD. Analyses were conducted with and without these 7 individuals, and the results were the same; therefore the analyses that we report on here include them.

In addition to the annual evaluations, clinicians also evaluated participants in the preclinical and nondemented groups at the time of death by using a retrospective interview with the collateral source a few days after death to assess the cognitive and physical status of the decedent prior to the terminal event but after the last clinical assessment (Berg et al., 1998). An experienced clinician then compiled an expiration summary for the participant in which prior clinical assessments, the postmortem retrospective interview, and pertinent medical records were reviewed and synthesized to summarize the entire course of the person’s participation in our studies. The clinician completed this expiration summary before autopsy findings were known and yielded a final expiration clinical diagnosis.

### Results

We observed substantial personality changes for the converters (see Table 1). Before receiving a clinical diagnosis of dementia, 47% of converters showed at least some change in personality. The most common personality changes in this group were increased rigidity (25%), growing apathy (24%), increased egocentricity (21%), and impaired emotional control (18%); the least common changes were diminished emotional responsiveness (9%) and purposeless hyperactivity (4%).

We found a similar pattern of change for the preclinical group; 50% of the individuals showed some personality change. Like the converters, changes that were most prevalent were increased rigidity (43%), growing apathy (21%), increased egocentricity (21%), and impaired emotional control (29%). Changes that were least prevalent were diminished emotional responsiveness (14%) and purposeless hyperactivity (0%). Even though the preclinical group did not show the cognitive decline required for a clinical diagnosis, they were equally likely as the converters to show some change in personality, $\chi^2(1, N = 82) = 0.04, p = .84$.

Both the converters and the preclinical group differed from the nondemented group, who showed relatively little change in personality. In fact, only 6 (23%) of the 26 nondemented individuals showed any change; 19% showed increased rigidity, but this was the only noteworthy change (see Table 1). Thus, twice as many individuals with dementia (established by means of clinical diagnosis or autopsy) showed some change in

### Table 1. Change in Personality by Diagnostic Group

<table>
<thead>
<tr>
<th>Personality Change</th>
<th>Nondemented</th>
<th>Preclinical</th>
<th>Converters</th>
</tr>
</thead>
<tbody>
<tr>
<td>n = 26</td>
<td>n = 14</td>
<td>n = 68</td>
<td></td>
</tr>
<tr>
<td>Purposeless hyperactivity</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>3 (4%)</td>
</tr>
<tr>
<td>Diminished emotional responsiveness</td>
<td>0 (0%)</td>
<td>2 (14%)</td>
<td>6 (9%)</td>
</tr>
<tr>
<td>Coarsening affect</td>
<td>1 (4%)</td>
<td>2 (14%)</td>
<td>7 (10%)</td>
</tr>
<tr>
<td>Loss of concern for others</td>
<td>0 (0%)</td>
<td>3 (21%)</td>
<td>6 (9%)</td>
</tr>
<tr>
<td>Impaired emotional control</td>
<td>1 (4%)</td>
<td>4 (29%)</td>
<td>12 (18%)</td>
</tr>
<tr>
<td>Increased egocentricity</td>
<td>1 (4%)</td>
<td>3 (21%)</td>
<td>14 (21%)</td>
</tr>
<tr>
<td>Growing apathy</td>
<td>2 (8%)</td>
<td>3 (21%)</td>
<td>16 (24%)</td>
</tr>
<tr>
<td>Increased rigidity</td>
<td>5 (19%)</td>
<td>6 (43%)</td>
<td>17 (25%)</td>
</tr>
<tr>
<td>Any change</td>
<td>6 (23%)</td>
<td>7 (50%)</td>
<td>32 (47%)</td>
</tr>
</tbody>
</table>

Notes: Values for Nondemented and Preclinical groups are at the last clinical assessment before death. Both groups had expiration clinical diagnoses of no dementia, but the preclinical group had a neuropathological diagnosis of Alzheimer’s disease at autopsy. Values for Converters represent personality changes before clinical diagnosis changed from no dementia to dementia.

### Measures

As part of the annual interview with the collateral source, the clinician asked the informant “about specific [personality] changes” based on eight items from the Blessed Dementia Scale (Blessed et al., 1968): increased rigidity, increased egocentricity, loss of concern for feelings of others, coarsening of affect, impaired emotional control, diminished emotional responsiveness, growing apathy, and purposeless hyperactivity. Each item was scored by the clinician as present (yes, that change had occurred) or absent (no, that change had not occurred). The data we report on here are from any of the annual assessments before the year in which the diagnosis of dementia was made, in the case of the converters, and from any of the assessments before death, in the case of the preclinical and nondemented participants.
personality compared with those with no indication of the disease, $\chi^2(1, N = 108) = 4.87, p < .03$.

**Conclusions**

Our prospective, longitudinal assessment of nondemented older adults allowed us to describe the very first changes in personality associated with dementia. Approximately half the people who either progressed to a clinical diagnosis of dementia or had the neurological markers of AD at autopsy experienced personality change before diagnosis. Less than one fourth of those who remained nondemented experienced personality change prior to death. These results add to prior research that has documented personality changes in dementia (e.g., Aitken et al., 1999; Siegler et al., 1994) and shown that personality changes accompany the progression of DAT (Petry et al., 1989; Rubin, Morris, & Berg, 1987). Our results suggest that observable personality changes may occur in the very earliest stages of the disease and precede measurable cognitive loss. If we want to detect the disease as early as possible so as to intervene most effectively, it may be inappropriate to require memory or other cognitive deficits for diagnosis. In some people, at least, the very first indication of the disease may be personality change. We also find it important to point out that the clinical diagnosis of DAT is probably made much earlier in the course of the disease by this particular research group than it is by other groups (Morris et al., 2001).

Regarding the nature of initial personality change, our results suggest that individuals become increasingly self-centered and inflexible before diagnosis. Although some may be more withdrawn and apathetic, others may be more impulsive and emotionally labile. This characterization extends findings from other research that also used the Blessed Dementia Scale. For example, the research by Bozzola and colleagues (1992) found a similar pattern of change in individuals already diagnosed with DAT, although the overall frequency of change for all personality elements was higher. The characterization of change from our study also adds to research that has used other measures of personality. Research with both the Neuroticism Extroversion Openness—Personality Inventory (NEO-PI; e.g., Chatterjee et al., 1992; Glosser et al., 1995) and bipolar ratings of personality attributes (e.g., Aitken et al., 1999; Heinik et al., 1999) indicates that individuals already diagnosed with dementia change in undesirable ways: They are more neurotic, passive, aloof, withdrawn, rash, and immature. Across studies, it seems that people change in negative ways relative to their former selves but still retain personalities that are distinct across individuals, arguing against the emergence of a universal “Alzheimer personality.”

Despite the strengths associated with this study, it has several limitations worth noting. More sophisticated measures of personality such as the NEO-PI might yield more detailed and comprehensive information regarding what facets of personality change first and what degree of change is indicative of dementia. Ratings provided on the Blessed Dementia Scale, although easily administered, are also somewhat coarse. Informants indicate whether a type of change is present or absent. There is no consideration of the degree of change. Another limitation of the present study is the small sample size of the preclinical group; therefore, the data and conclusions about this group are subject to all the limitations common to small samples.

Although the positive predictive value of personality change was 87% in the current sample, the negative predictive value was only 32%. Our sample was heavily weighted with demented individuals, which might also be the case in geriatric or memory disorder clinics. In a sample more representative of the base rate in the population, which increases with age, these values would reverse. If we use a 20% base rate as an example, then the positive predictive value of personality change would be 34% and the negative predictive rate 82%. Thus, the diagnostic value of personality change will vary with context.

It is widely acknowledged that informant reports about demented individuals can be biased, despite recent studies that support the reliability and validity of informant reports (Chatterjee et al., 1992; Heinik et al., 1999; Strauss et al., 1993). As dementia progresses, self-reports from patients about some phenomena become less reliable, and for a construct such as personality, informants may be the best source of information short of actual behavioral observations. It is not clear, however, if this is the case in the very earliest stages of the disease, when cognitive deficits are essentially undetectable. Some people may have better access to some of their own personality characteristics than even a knowledgeable informant could ever be expected to describe.

An issue that this line of research may eventually address is how to discriminate between different types of dementia on the basis of early personality change. Initial research in this area shows promise. Personality change can be used to differentiate frontotemporal dementia from DAT at later stages of the disease (e.g., Barber, Snowden, & Craufurd, 1995; Mychack et al., 2001) and to differentiate among head injury, stroke, and DAT (e.g., Golden & Golden, 2003). Early, unique personality change associated with different types of dementia may improve differential diagnosis.

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