
Insight in Alzheimer's patients: Results of a longitudinal study using three assessment methods

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Abstract

Three direct measures of dementia insight were administered to 20 participants in a longitudinal Alzheimer's disease (AD) rehabilitation research project¹ and to subsets of these participants that completed one ($N = 19$), two ($N = 12$), and three ($N = 6$) years of program participation. The measures were: (1) responses to a discourse prompt question about AD (ADPQ); (2) endorsements of seven items on the Geriatric Depression Scale² (GDS) about the effects of dementia (separate analyses were done for two of the seven items that related specifically to memory and thinking); and (3) a sentence-completion exercise. Responses to measures 1 and 2 and the subset of 2 were quantified, tracked over time, and subjected to correlational analyses with age, Mini-Mental State Exam³ (MMSE) score, and depression, as measured by total GDS score, and with each other.

Major findings: There were no decreases in insight from baseline to year 1, 2, or 3, as measured by free responses to the AD prompt question. There was a significant decline in insight from baseline to year one on the GDS measure, but no change from year 1 to year 2 and a return to baseline level at year 3. There was no correlation between insight and baseline age, between insight and MMSE score at any time point, between MMSE score and depression, as measured by total GDS score, or between MMSE score and depression score, except for the year 3 completers, where depression score was negatively correlated with MMSE score at year 3 only.

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GDS insight and ADPQ scores were not correlated. Several participants that showed no insight on the quantified measures did so on the sentence completions.

Prologue

In 1997, an editorial⁴ was published in the *Alzheimer Disease and Associated Disorders*, which faulted most studies of insight or awareness of dementia for "insufficient attention to the variability in unawareness within individuals and within diagnostic groups." This paper is about attention to such variability.

Transcripts of patient responses that counter prevalent beliefs about insight in Alzheimer's patients personalize the group data presented here and constitute a response to those insight researchers that call for attention to patient variability.⁴⁻⁶

Introduction

Many studies of Alzheimer's disease (AD) and insight assess insight via response to nonstandard questions during a diagnostic interview, such as "Why are you here?" or "Are you experiencing memory problems?"⁷ Others judge insight according to how accurately the patients predict performance on future tasks⁸ or rate their own skills in comparison to caregiver ratings.⁹⁻¹¹ Most insight studies are cross-sectional. They either compare AD patients of different cognitive levels,^{12,13} or AD patients with persons who have other dementing disorders at one point in time.¹⁴ Evidence from the few extant longitudinal studies^{11,15} has been equivocal, which highlights the need for further research in this area.

Because the more impaired AD patients demonstrate

lack of insight more often than the mildly impaired, the unwarranted conclusion is drawn that insight decreases as severity of dementia progresses. In this paper, we present results of multi-method and repeated assessments of AD patients' insight over time. We observed that possession of insight is idiosyncratic, rather than stage-related, and that patients who show insight at the time of initial assessment tend to maintain that insight over time, even though their ability to express it may deteriorate. Transcripts of patient responses are presented to illustrate both dissociation between cognitive level and insight, and maintenance of insight despite disease progression.

Background

This section recounts the origins of the first author's interest in and early experiences with insight and its assessment. Because of this discussion's anecdotal nature, it is written in the first person.

My fascination with the phenomenon of insight in AD patients was sparked in 1987, during the first year of my doctoral studies in psychology, by observations of my mother, Bee, who was diagnosed with AD that year. I was struck by the fact that, despite the dramatically reduced scope of Bee's social and community involvements, and her virtually intact conversational ability, she would talk about playing mahjonn, going to the symphony and theater, and driving her neighbors to the doctor—activities which had been abandoned several years prior—as if they were still part of her regular routine.

Origin of assessment methods

Sentence completions. During my internship at the University of California at Irvine, I began working with Dick, an AD patient who was at the same mental status level as Bee. To my surprise, I found that he was acutely aware of the reduced scope and complexity of his activities. Eager to capture this insight on video, I created a series of sentence stems for him to complete to assist him to tell his story. Following is a partial transcript of a sentence-completion exercise with Dick, administered when he was 58 years old and had an MMSE score of 23.

Stem: Before I started having problems, I thought that Alzheimer's...was for old people.

Stem: Since I've had Alzheimer's, I feel angry that...it had to be me!

Stem: Since I've had Alzheimer's, I especially appreciate...the support that I've got from Carol [his wife].

Stem: Since I've had Alzheimer's, I miss...work—my work—being able to work on vehicles and change 'em around the way I wanted to.

Stem: Since I've had Alzheimer's, I've learned to enjoy...My family and my friends have become more precious than they were before.

Stem: Since I've had Alzheimer's, my wife...My wife—my wife and I have essentially and in many ways reversed roles.

Stem: Since I've had Alzheimer's, my son Jim...I guess—what comes to mind—he's kind of in a way become the man of the house.

Stem: Since I've had Alzheimer's, I get embarrassed when...I can't—in conversing with somebody, I do get embarrassed when the mind just quits, and so that's one of the reasons why early on I got it out to the neighbors and everybody else...so they know where, what,...that I'm not a dummy. I just can't grab the words sometimes.

Stem: If I tell a story for the second or third time...Tell me you've already said it!

[My question:] It won't hurt your feelings? [His answer:] Not at all.

The tremendous variability in insight was further illustrated by another patient, Dorothy (age 86, MMSE: 22), of the same (early-stage) mental status level as Dick and Bee, but who demonstrated not only total lack of insight, but “off-the-wall” confabulations in responses to sentence stems that elicited such profound and abstract responses from Dick. Parts of her transcript are produced below.

Stem: Before I started having memory problems, I thought that Alzheimer's was...the product, no, was the medicine, no, Alzheimer's was the thing that would make you well.

Stem: I knew that something was wrong with me when...I was going to work that morning. I had a terrible, terrible pain in my mouth...I was having trouble with my teeth and 12 o'clock that afternoon. I had to leave my job and go to the dentist and from then on, I'm fine. [Repeated references to a dentist probably stem from the fact that she had been a billboard model in her later years, advertising a dental practice.]

Table 1. Varying patterns of insightful statement production in response to AD discourse prompt questions (ADPQ) compared to GDS total insight and GDS flag (memory) items endorsed (* = 1 GDS flag; ** = 2 GDS flag)

Subject: Baseline/ Final MMSE	Baseline	Year 1	Year 2	Year 3	Comments
<i>No insight statements ever produced in response to AD discourse prompt questions</i>					
BM: 29/27	0 (1)	0 (1)	0 (1)*	0 (2)	Insight on sentence completion; compliant with treatment
DK: 26/20	0 (3)**	0 (3)**	0 (1)*	0 (4)**	
EB: 22/26	0 (4)**	0 (2)			
WM: 22/12	0(1)	0 (1)	0 (1)*		No insight on sentence completion; denial; compliant
RK: 22/9	0 (3)*	0 (2)			
ES: 21/18	0 (2)*	0 (0)			Insight on sentence completion; denial; compliant
LA: 18/16	0 (1)	0 (0)	0 (2)*		Insight on sentence completion; denial; noncompliant
<i>Minimal insight demonstrated in response to AD discourse prompt questions</i>					
DC: 26/17	0 (4)**	1 (3)**	0 (1)		
EM: 23/10	0 (1)*	2 (0)	0 (0)		Insight on sentence completion; denial; compliant
<i>Consistent or increasing production of insightful responses to AD discourse prompt questions</i>					
MD: 29/24	3 (6)*	1 (4)*			
DG: 27/21	11 (5)**	16 (1)*	8 (1)		See footnote 1 below
EMc: 26/19	3 (4)**	1 (5)**	2 (1)*	4 (2)**	See footnote 2 below
NM: 23/20	0 (6)**	1 (5)**	2 (5)**	3 (5)*	See footnote 3 below
LR: 22/22	2 (4)**	2 (6)**			Much denial; noncompliant
IJ: 17/13	7 (5)**	10 (0)	5 (3)	6 (4)**	Denial; compliant
HC: 15/5	3 (4)*	1 (6)**	6 (7)**	0 (5)*	See footnote 4 below
<p>1. Note consistently large numbers of insightful ADPQ responses, in contrast to relatively few and decreasing number of GDS insight items endorsed.</p> <p>2. Note consistent production of both insightful ADPQ and GDS insight responses.</p> <p>3. Note zero to steadily increasing number of ADPQ responses and consistently large number of GDS insight responses.</p> <p>4. Too aphasic to respond by year 3. Note consistently large number of GDS insight responses.</p>					

Stem: The thing I fear most about Alzheimer's is...Oh, that's terrible...even with fruits and with vegetables. You can eat a fruit and get very, very sick on it if you don't know particularly which one it was. The Alzheimer's disease, I've known a little bit about it when I was young—but since then—I've had...I'm fine.

Stem: Since I've had Alzheimer's, I've had to give up...I've had to give up...[pause]...a library book because the doctor and the dentist were on the same par. And once I had to go to the dentist and once I had to go to the doctor at the same hour on the same day...

Dorothy also exhibited time disorientation in her description of current daily activities, producing, like Bee, a description of activities in which she formerly, but no longer, engaged. Weinstein and colleagues¹⁶ have linked such a pattern of confabulation and disorientation for place and time to lack of awareness.

I maintained contact with Dick as his dementia progressed. The following sentence completion was produced three years after the previously presented transcript was made, when his MMSE score was 12 and his language ability was severely compromised. Despite severe anomia, he produced a concrete version of a previously abstract, insightful sentence completion.

Stem: Since I've had Alzheimer's, my wife Carol...uh—well, she's now the, uh—she does all the bills and...all the...those type of...And I've let go of the car because I was afraid I might hurt myself or somebody else.

[My question:] So, Carol has more responsibility now? [His answer:] She sure does!

I continued to use sentence completions as part of the intake interview for two pilot rehabilitation studies.^{17,18} The stems used varied in wording and number, depending on the number of family members in the person's life and other personal circumstances. If the person or the person's family acknowledged or identified with an AD diagnosis, the term "Alzheimer's disease" was used in the stem. If not, the term Alzheimer's disease was substituted with the phrase "memory problems."

Alzheimer's discourse prompt question (ADPQ). When the discourse-assessment battery was being developed for my longitudinal AD Rehab by Students project, I decided to include a question about Alzheimer's disease in the expository discourse category, hoping that information about insight would be elicited in addition to

the language-quality information being sought. The prompt question used was: "Tell me what you know about Alzheimer's disease." If no reference to AD affecting self was made, follow-up questions were asked: "Has Alzheimer's disease affected you or your family in any way? [If yes:] How?"

Sentence completions were obtained during administration of the above-mentioned discourse battery, but uniformity of administration was sometimes sacrificed in order to obtain meaningful or expanded responses. (See the section on Data Scoring and Analysis for an explanation as to how sentence-completion data were used.)

Geriatric Depression Scale (GDS) insight questions. Use of the GDS to assess insight was a *post-hoc* decision; the GDS was originally administered to monitor depression levels in our participants. Two years into our study, we noticed that a number of questions in the 30-item GDS protocol, if answered in the "depressed" direction, could just as easily be interpreted as indicating awareness of the effects of dementia. Two such items are specifically memory-related:

GDS item 14: Do you feel you have more problems with memory than most?

GDS item 30: Is your mind as clear as it used to be?

We came to refer to these items as *GDS flag* items. Other GDS items relate to common effects of Alzheimer's disease:

GDS item 2: Have you dropped many of your activities and interests?

GDS item 13: Do you frequently worry about the future?

GDS item 20: Is it hard for you to get started on new projects?

GDS item 26: Do you have trouble concentrating?

GDS item 29: Is it easy for you to make a decision?

These (together with the "flag" items) are referred to as *GDS insight* items.

Methodology

Study participants

All participants were community-dwelling Alzheimer's

Table 2a. Insight over time: One-year completers (n = 19)		
	Scale	Baseline
Year 1	GDS insight	-2.24*
	GDS flag	-1.67
	ADPQ insight	+0.82
* significant at the 5 percent level of significance ** significant at the 1 percent level of significance t values from paired t-tests comparing different measures of insight over time. Sample is all patients who have values of the variables for each time point (n = 20). A negative t value shows a decline while positive t value shows improvement (a zero shows no difference).		

patients enrolled in the University of Arizona's AD Rehab by Students program, a five-year intervention study funded by the National Institute on Aging (NIA). Ages at time of enrollment ranged from 59 to 86 years old, with most of the participants in their late 70s or 80s. All participants were assessed and diagnosed according to criteria established by the Consortium to Establish a Registry for Alzheimer's disease (CERAD)¹⁹ by CERAD-certified clinicians. Baseline MMSE scores ranged from 15 to 29.

Baseline correlational data are reported for 20 participants for whom such information was available. First-year data are reported for 17 to 19 one-year program completers, second-year data for 12 completers, third-year data for five to six completers, depending on the measure involved. Two or three transcripts of interviews are missing because of mechanical failure of recording equipment or loss of the disks on which interviews had been transcribed and typed by a student.

Baseline and annual assessments

Alzheimer disease prompt question (ADPQ). Baseline and first annual responses to the AD prompt question were elicited by the principal investigator (Arkin) at the participant's home as part of a comprehensive discourse battery that was analyzed for language quality as one of the study's outcome measures. (See reference citing our earlier work.²⁰) The session was both videotaped and audiotaped. The audiotape was then transcribed verbatim by each participant's student partner. (See Arkin^{18,21} for a description of the rehab partner's role). Second- and third-year testing sessions were conducted

by the principal investigator at the participant's home or a university office.

Sentence completions. During the project's second year, an attempt was made to standardize the content and administration of the sentence-completion task. Eight sentence stems were selected to be included in all future administrations of the task, based on their representative content and presence in the transcripts of most of the prior interviews. The selected stems were:

1. Since I've had memory problems (or Alzheimer's), I worry that _____.
2. I realized I had a memory problem when _____.
3. Since I've had a memory problem, (name of caregiver) _____.
4. Since I've had a memory problem, I've had to give up _____.
5. Since I've had a memory problem, it's harder for me to _____.
6. Since I've had a memory problem, I need help with _____.

Table 2b. Insight over time: Two-year completers (n = 12)			
	Scale	Baseline	Year 1
Year 1	GDS insight	-1.86	
	GDS flag	-1.00	
	ADPQ insight	+1.17	
Year 2	GDS insight	-2.93**	-0.63
	GDS flag	-1.32	-0.82
	ADPQ insight	0.00	-0.71
* significant at the 5 percent level of significance ** significant at the 1 percent level of significance t values from paired t-tests comparing different measures of insight over time. Sample is patients in study for two years (n = 12). A negative t value shows a decline while positive t value shows improvement (a zero shows no difference).			

Table 2c. Insight over time: Three-year completers (n = 6)

	Scale	Baseline	Year 1	Year 2
Year 1	GDS insight	-0.50		
	GDS flag	+0.00		
	ADPQ insight	0.00		
Year 2	GDS insight	-1.94	-0.70	
	GDS flag	-1.17	-2.24*	
	ADPQ insight	+0.44	+0.25	
Year 3	GDS insight	-0.31	+0.35	+2.23*
	GDS flag	-1.00	-0.35	+0.67
	ADPQ insight	0.00	0.00	-0.28

* significant at the 5 percent level of significance
 ** significant at the 1 percent level of significance
 t values from paired t-tests comparing different measures of insight over time.
 Sample is patients in study for two years (n = 6).
 A negative t value shows a decline while positive t value shows improvement (a zero shows no difference).

7. Since I've had a memory problem, I get frustrated when _____.

8. When I think about the future, _____.

The sentence-completion task was administered by the principal investigator as part of the discourse battery at the participant's home or a university office, at baseline and annual intervals.

Geriatric Depression Scale (GDS). The GDS was administered strictly as a depression measure by the principal investigator at intake and after the first year, at participants' homes. At the end of the second and third year of treatment, the GDS was administered by a psychology doctoral student under the supervision of a CERAD-certified neuropsychologist, either at participants' homes or a university office.

Scoring of insight data

Responses to the ADPQs. The co-investigator (Mahendra) did the initial scoring of all ADPQ responses, according to criteria developed for identifying "topic comments" in participant discourse.²⁰ It soon became apparent that the criteria we were using were not stringent enough to distinguish truly insightful statements

from vague, though linguistically correct, responses. Close examination of numerous transcripts revealed three types of statements that we decided to code and count: (1) factually correct general-knowledge statements about Alzheimer's (coded as "K" or knowledge responses); (2) statements relating Alzheimer's or any of its symptoms to self (coded as "I" or insight responses); and (3) statements which disavowed any personal connection with Alzheimer's, made joking references to Alzheimer's, asked the examiner if she thought she had the disease, or defensively stated unwillingness to talk about the disease or know about it (coded as "D" or denial responses).

The ADPQ transcripts were then independently re-scored by both investigators according to the new criteria. Scores assigned to 100 statements were compared and found to be in agreement 96 percent of the time. Disagreement on the four disparately scored items was resolved by consensus.

More often than not, the utterance of a denial response is indicative of an awareness, however slight or buried, that Alzheimer's is or in the future may be affecting the speaker. The denial response is a form of defense against conscious acknowledgment of an unpleasant reality. The mode of response—whether joking, challenging, reassurance-seeking, angry, or a refusal to discuss—varies

Table 3. Frequency of GDS insight items endorsed at various time points (in percent)

	Baseline	Year 1	Year 2	Year 3
Dropped activities	13.04	13.04	8.33	9.09
Worry about future	4.35	4.35	4.17	4.55
Difficulty starting new projects	15.94	13.04	12.50	22.73
Difficulty concentrating	13.04	17.39	16.67	18.18
Difficulty making decisions	13.04	8.70	20.83	9.09
*Memory problems	18.84	17.39	16.67	13.64
*Mind clear	21.74	26.09	20.83	22.73
* Total flag items	40.58	43.48	37.50	36.37

according to the personality of the respondent and is probably consistent with the individual's response style in similar unpleasant situations.

Sentence completions. Despite best intentions, the principal investigator did not consistently administer some of the second- and third-year sentence-completion interviews and baseline interviews with new program participants. One reason was that, at the later years, because of decline in language functioning, more prompts and more specific prompts were often required to elicit meaningful discourse. In the case of new participants, several were so eloquent and insightful in their responses that it was deemed more important to encourage them to elaborate by asking nonstandard follow-up questions, than to stick to an arbitrary protocol.

Therefore, we abandoned our initial efforts to quantify and code sentence-completion responses, though we plan to do so in the future. However, we have used these data in two ways: (1) to document instances where participants who failed to demonstrate insight via ADPQ or GDS responses produced insightful sentences by this method (see Table 1), and (2) in several demonstration transcripts that used sentence stems in addition to the "official" eight.

The following baseline sentence completions were produced by a highly insightful 72-year-old woman with an MMSE score of 16, commonly regarded as indicative of moderate dementia:

Since I've had Alzheimer's, I fear...getting worse.

Since I've had Alzheimer's, I feel sad that...everybody has to do things for me.

Since I've had Alzheimer's, I miss...going and doing things by myself.

Since I've had Alzheimer's, I worry...about getting lost; that people will get tired of listening to me when I repeat myself.

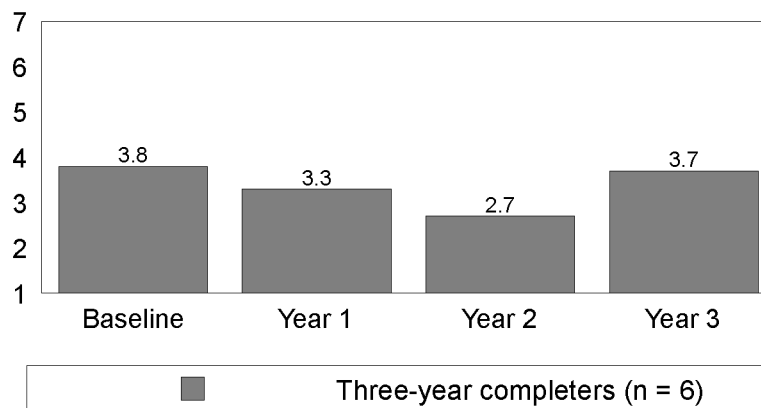
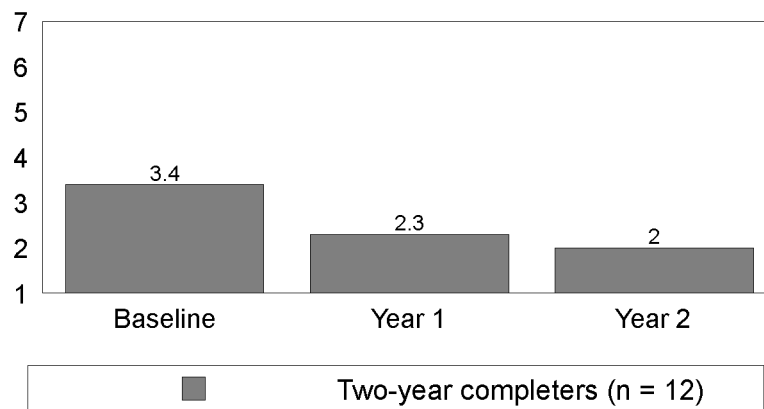
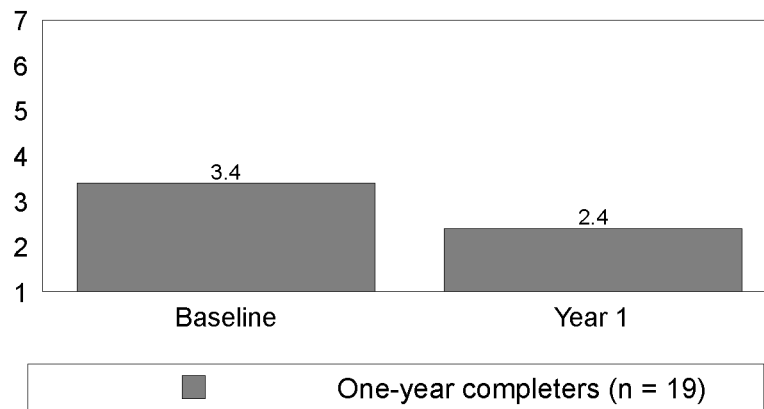
Since I've had Alzheimer's, I've had to give up...driving...and my husband has decided he can cook!

Since I've had Alzheimer's, I need help with...I don't go out without telling somebody where I'm going.

Since I've had Alzheimer's, I feel frustrated when...people don't understand what I'm trying to tell them. When I can't think of a word I want to say, I'll say, "You know what I mean!"

These and excerpts from other interviews like them have become priceless videotaped testimonies of AD patients' insight about their disorder and its effects on their lives.

GDS responses. The GDS protocols were scored by the examiners who administered them. Analysis and tabulation of the identified insight or flag responses



**Figure 1. Mean insight score on seven dementia-related GDS items: By cohort (*p < 0.05).
* Indicates significant difference from baseline score.**

Table 4. Individual insight and MMSE scores

	Subject/Baseline age								
	LA/78	AB/78	DC/79	HC/82	IJ/83	DK/83	BM/86	EMc/78	NM/58
<i>Free responses to AD prompt question: Bold = insight statements; D = denial statements; K = knowledge statements</i>									
Baseline	0, 0D, 0K	0, 0D, 3K	0, 0D, 2K	3, 0D, 2K	7, 0D, 1K	0, 0D, 4K	0, 0D, 2K	3, 0D, 4K	0, 0D, 1K
Year 1	0, 0D, 2K	0, 0D, 2K	1, 0D, 2K	1, 0D, 2K	10, 0D, 1K	0, 0D, 2K	0, 0D, 1K	1, 0D, 2K	1, 3D, 3K
Year 2	0, 3D, 0K	1, 0D, 2K	0, 0D, 1K	6, 0D, 2K	5, 0D, 1K	0, 0D, 2K	0, 0D, 1K	2, 0D, 2K	2, 0D, 2K
Year 3				0, 0D, 0K	6, 2D, 0K	0, 0D, 0K	0, 0D, 3K	4, 1D, 0K	3, 0D, 3K
<i>Total GDS insight items endorsed: Max = 7 (memory-related items endorsed: Max = 2)</i>									
Baseline	1 (0)	6 (2)	4 (2)	4 (1)	5 (2)	3 (2)	1 (0)	4 (2)	6 (2)
Year 1	0 (0)	3 (1)	3 (2)	6 (2)	0 (0)	3 (2)	1 (1)	5 (2)	5 (2)
Year 2	2 (1)	3 (1)	1 (0)	7 (2)	3 (0)	1(1)	1 (1)	1 (1)	5 (2)
Year 3				5 (1)	4 (2)	4 (2)	2 (0)	2 (2)	5 (1)
<i>MMSE</i>									
Baseline	18	24	26	15	17	26	29	26	23
Year 1	14	25	24	9	18	26	29	20	20
Year 2	16	20	17	8	15	24	28	23	20
Year 3				5	13	20	27	19	20

were done by the project’s statistical consultant from the item-by-item scores that had been entered into a database.

Data analysis

Pearson correlation coefficients were calculated for: (a) baseline age and insight, as measured by GDS insight responses, for 20 participants; (b) for baseline, first-year (N = 19), second-year (N = 12), and third-year (N = 6) MMSE scores and the three quantified insight measures (the ADPQs, GDS insight, and GDS flag responses); (c) between MMSE scores and depression, as measured by total score on the GDS; (d) between ADPQ insight scores and depression; and (e) between the three insight measures. Item analyses of endorsed items on the GDS at each time point were also done. Paired t-tests were conducted to assess and monitor change in mean group responses on the three quantified insight measures between the annual testing occasions.

Results

Age and insight

There was no correlation between insight-related items endorsed by 20 participants prior to beginning treatment and baseline age ($r = 0.35, p = 0.12$). (Data set includes one participant who dropped out without completing one year of treatment.)

Insight over time

One-year completers. Insight, as measured by GDS insight item endorsements for 19 one-year program completers declined significantly from baseline to year 1, [$t(18) = -2.24, p < 0.05^*$]. On the subset of two flag (memory-related) GDS items, this same cohort had a nearly significant decline [$t(18) = -1.68, p = 0.0553$]. These results differed from those of Sevush,¹⁵ who reported no change in AD patients’ judgment of their

Table 4. Individual insight and MMSE scores (continued)

	Subject/Baseline age								
	MD/85	EM/83	DG/74	EB/88	LR/79	WM/79	RK/73	ES/88	MC/66
<i>Free responses to AD prompt question: Bold = insight statements; D = denial statements; K = knowledge statements</i>									
Baseline	3 , 0D, 2K	0 , 0D, 0K	11 , 0D, 2K	0 , 0D, 13K	2 , 1D, 1K	0 , 0D, 0K	0 , 0D, 2K	0 , 0D, 1K	7 , 0D, 1K
Year 1	1 , 0D, 1K	2 , 0D, 0K	16 , 0D, 3K	0 , 0D, 8K	2 , 7D, 1K	0 , 0D, 0K	0 , 0D, 0K	0 , 0D, 0K	
Year 2		0 , 0D, 0K	8 , 0D, 2K			0 , 0D, 0K			
Year 3									
<i>Total GDS insight items endorsed: Max = 7 (memory-related items endorsed: Max = 2)</i>									
Baseline	6 (1)	1 (1)	5 (2)	4 (2)	4 (2)	1 (0)	3 (2)	2 (1)	5 (2)
Year 1	4 (1)	0 (0)	1 (1)	2 (2)	6 (2)	1 (0)	2 (0)	0 (0)	
Year 2		0 (0)	1 (0)						
Year 3									
<i>MMSE</i>									
Baseline	29	23	27	22	22	22	22	21	16
Year 1	24	17	23	26	22	16	9	18	
Year 2		10	21			12			
Year 3									

memory impairment between baseline and 15 months later. On responses to the AD prompt question, the present group showed no change [t(16) = 0.82, p = 0.79]. (See Table 2a.)

Two-year completers. Insight, as measured by the GDS insight test for 12 two-year program completers showed no change from the end of year 1 to the end of year 2 [t(11) = -0.63, p = 0.27]. On the subset of two flag (memory-related) GDS items, this same cohort again showed no change [t(11) = -0.82, p = 0.21]. On responses to the AD prompt question, this group showed no change from year 1 to year 2 [t(11) = -0.71, p = 0.25]. (See Table 2b.) Thus, the subset of two-year completers more closely resembled Sevush's¹⁵ group.

Three-year completers. This hardy group of six showed no change from baseline to year 3 [t(5) = -0.31, p = 0.39]. Interestingly, their GDS insight score showed a nearly significant decline from baseline to end of year 2 [t(5) = -1.94, p = 0.055], but by year 3, their score had returned to its baseline level. On the two

GDS flag (memory-related) items, the group showed no change from baseline to end of year 3 [t(5) = -1.00, p = 0.18]. On the AD prompt question, the three-year group again showed no change from baseline to year 3 [t(5) = 0.001, p = 0.50]. (See Table 2c). These outcomes in relationship to the three cohorts are displayed in Figure 1.

Most frequently endorsed GDS items

At baseline, 41 percent of all endorsed insight-related items were the memory-related flag items (“mind clear” and “memory problems”). At year 1, those same two items accounted for 43 percent of responses. At year 2, they accounted for 37.5 percent, but “difficulty making decisions” replaced the “memory problems” as the second most frequently chosen item (21 percent). At year 3, “difficulty starting new projects” tied with “mind clear” for first place (23 percent each), with trouble concentrating coming next (18 percent).

MMSE and insight correlations

There was no correlation between MMSE and any of the insight measures (ADPQ, GDS insight, and GDS flag) at baseline, year 1, year 2, or year 3. The GDS insight and ADPQ response tests were also unrelated at all time points. There were significant correlations between the GDS flag and GDS insight test results (at baseline and year 1), but this is explained by the fact that one is a subset of the other.

MMSE, insight, and depression

MMSE scores and depression were unrelated at all time points except year 3, where mean MMSE score for six participants was negatively correlated with depression ($r = -0.82$, $p < 0.05^*$), meaning that lower MMSE scores were significantly associated with higher GDS depression scores. Depression, as measured by total GDS scores, was unrelated to scores on the AD prompt question responses at all time points. Depression was significantly correlated with the GDS insight measure at baseline ($r = 0.70$, $p < 0.001^*$), an expected finding because one measure is a subset of the other.

Conclusions and discussion

In this section, the reader should note that conclusions are in boldface type, participants' discourse is in italics, with supporting discussion following in regular type.

Results from this study clearly show that insight in persons with Alzheimer's disease is idiosyncratic. This would explain the contradictory findings of published studies on the subject. Unlike other studies, the present one both used multiple measures and assessed the same people over time. For individual scores on the ADPQ (including knowledge and denial responses) and on the GDS insight and flag items, see Table 4.

In this study, unlike in most others, there was no correlation between insight and mental status level, and glaring contradictions to the oft-cited linear association between mental status and insight were observed. This relationship was assessed at four different time points over a three-year period. In all the following examples, statements in response to the ADPQ are coded as they were for analysis: I for insight, K for knowledge, and D for denial statements.

HC, a severely impaired individual (MMSE = 8), in response to the AD prompt question at year 2, responded: *"You get all scared up (I) and not knowing what you're...what I was doing and things like that (I). I don't think like I used to (I). And I don't know what's going on (I). My mother had it. (I)"*

BM, the participant with the highest mental status in the program, consistently mixed partial knowledge statements, referring vaguely to mental disease or not being able to remember something, with confabulations. In response to the ADPQ in year 2, when her MMSE score was 28: *"Well, I got the beginnings of it, I expect...This shoulder...nearly everyone that I have known that have had the beginning of Alzheimer's is affected with these rounded shoulders and some back problems, probably."* At baseline, she went off on a tangent about AD patients' alleged inability to write: *"I understand a lot of them cannot write a letter, but they can type it out on the typewriter. But writing, holding a pen, is something that they can't do."*

BM's confabulations—some complete fabrications (e.g., Mrs. Eisenhower having made her a birthday cake when they were allegedly next-door neighbors), others embellishments of past accomplishments—were not accompanied by disorientation for time and place, an association found by Weinstein, Friedland, and Wagner.¹⁶ (The Eisenhower story was so convincing, co-author Arkin actually e-mailed the Abilene, Kansas Historical Society to compare addresses of the Eisenhower family and BM's family in 1910. They were *not* neighbors!)

Dorothy, the early-stage patient whose bizarre transcript was contrasted with Dick's insightful one earlier in this paper, did have the type of disorientation found by Weinstein and colleagues.¹⁶ She gave detailed descriptions of her daily activities that were accurate as of two or three years prior, but unrelated to her current life situation. Several other low-insight participants (DC and RK in Table 1) were also observed to confuse past and present reality, speaking of deceased parents or spouses as if they were still alive.

The commonly held assumption that insight decreases with time and disease progression was also not supported. Only at one time point—from baseline to one-year post-treatment—did insight, as measured by GDS insight, show a significant drop. This cohort also had a significant decline in MMSE score. However, there was no change from year 1 to year 2, and persons who completed year 3 actually returned to their baseline insight level. (See Figure 1.) This may be simply a reflection of their overall robustness, or, more likely, that robustness combined with the physical, social, and cognitive benefits derived from long-term participation in the program.

Some participants demonstrated increased insight over time. NM, age 59, who made two knowledge responses and no insight responses at baseline, volunteered that his memory was bad at year 1, but explained it as follows: *"I think I had an injury to my head (D) or whatever it was caused my brain to shrink (D). I can't*

remember all the details. I don't think I have Alzheimer's disease (D)." At year 2, he stated, "My memory is not very good (I) and there are some chores I have trouble doing (I)." His year 3 response, helped along by a direct question, was both knowledgeable and insightful. "Alzheimer's disease...it's a brain...a disease that attacks the brain (K), uh,...generally older people contact [sic] it (K)...It's, uh,...you have a memory loss (K)"

Prompt: Have you and your family been affected by it in any way? "No...No, my family's never had Alzheimer's. (D)"

Prompt: What about you? "Uh,...Yes, I probably have Alzheimer's. (I)"

Prompt: How is it affecting you? "Memory loss (I). Can't do complicated work. (I)"

Presence of insight tends to be consistent within individuals, though the ability to verbalize it may diminish as the disease progresses. Recall how Dick was still insightful about his and his wife's reversed roles three years after initial assessment. HC, whose insightful year 2 responses were previously cited, was extremely aphasic by year 3 (MMSE = 5) and could make no meaningful responses to the prompt question or the sentence-completion task. Yet she endorsed five of the seven GDS insight responses. Her mean number of such responses for four testing occasions over three years (5.5) was the highest of our entire group.

Multiple means of assessing insight yield more information than a single measure. Three participants who had zero scores on their ADPQ responses and very few GDS insight endorsements, nevertheless showed substantial insight on their sentence completions. (See Table 1 and examples that follow.)

Example 1: BM

Since I've had a memory problem, I've had to give up...the idea of getting a job.

Since I've had a memory problem, I need help with...handling finances.

Example 2: ES

Since I've had a memory problem, I need help with...remembering when to go where.

Since I've had a memory problem, I've had to give up...I can't think of anything. That's an example of my memory problem!

Example 3: LA

Since I've had a memory problem, I've had to give up...driving the car.

Since I've had a memory problem, it's harder for me to...I've just slowed down a bit. I talk a little slower.

A response to the Alzheimer's-related prompt question that spontaneously acknowledges effects of AD on self is probably the measure most indicative of high insight because it is freely produced, without structure provided by the examiner.

Sentence-completion items need to be looked at qualitatively. They may be general, platitudinous responses, or they may give specific information, e.g., "Since I've had a memory problem, my wife 'helps me' versus my wife 'now does all the driving, pays all the bills.'"

Insight regarding memory loss seems to be more readily acknowledged than diminished ability or responsibility in reference to activities of daily living. This was demonstrated by the more frequent endorsement of the GDS flag (memory-related) items, relative to the items that acknowledge diminished capabilities, need for help, and reduced scope of activities. (See Table 2.)

All of our depressed patients demonstrated insight. However, most of our AD patients, including insightful ones, were not depressed. Depression, when present, should be treated with the introduction of pleasurable, esteem-building activities and medication, if indicated.

Insight is unrelated to age in our sample (statistically, as well as anecdotally). One 54-year-old patient, forced to retire from her job at age 53, has total insight; another, age 58 at program entry and forced to retire at 57, failed to acknowledge his AD diagnosis until the end of his third year of treatment.

Denial, not lack of insight, may be associated with noncompliance. Noncompliance with treatment is said to be associated with lack of insight.²² However, there were several patients without insight who were wonderfully compliant—both with their caregivers and our program (see EM, WM, and ES in Table 2). Of two participants that were terminated for noncompliance, one had insight and one did not. However, both of the noncompliant participants made frequent denial statements in their sentence completions or ADPQ responses.

Refusal by an individual to accept limitations imposed by a handicapping condition can manifest itself in angry, acting out, even life-threatening behaviors, which cause enormous stress for the caregivers responsible for the care of such a person. On the other hand, such refusal can also be expressed via extraordinary compensatory efforts by persons with handicaps, leading to unusual

accomplishments and being looked upon as a role model for persons with similar handicaps.

For a person with a progressive memory disorder such as Alzheimer's disease, the setting of limits, the assumption of the demented one's prior responsibilities, and planning for his or her future sooner or later becomes the task of the caregiver responsible for the person with dementia. In the case of deniers, those that "protest too much" typically know or suspect deep down that something is seriously wrong. It is not hard to imagine that such individuals may be more inclined to resist efforts to help them and to fight actively against the loss of privileges, such as driving or handling a checkbook, or against efforts to enroll them in research or treatment programs. Seltzer and colleagues²³ specifically looked at the impact of AD patients' awareness on caregiver burden and found an association between impaired awareness and caregiver burden.

On the other hand, cognitively impaired individuals without awareness that something is seriously wrong may react with hurt feelings or feelings of betrayal when restrictions are placed on their freedom and someone takes over responsibilities they have been accustomed to handling. If these individuals acknowledge a memory problem, they tend to minimize it as one common to all people of advancing age. Such individuals may be very amenable to programs or treatments to improve their memory. They may recognize Alzheimer's as a serious disease of old age that affects other people, but will not identify it as something affecting them—even when they have been through comprehensive neurological and neuropsychological testing and been told the diagnosis.

All of our participants—irrespective of insight level—were required to give consent to every aspect of our program via a simplified consent form that required an item-by-item yes or no answer. Caregiver consent was also obtained, regardless of guardianship or power-of-attorney status, on a detailed "human subjects" information and consent form, required by the University of Arizona and the NIA.

Participants that did not acknowledge AD or whose family shielded them from an Alzheimer's diagnosis were not confronted with its reality. One newspaper article about the program, whose headline used the term "memory-impaired," rather than "Alzheimer's," was given to such patients as part of their orientation package, rather than articles that specifically mentioned AD.

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Note

**The program is known in the community as Elder Rehab because some participants or their families do not acknowledge an Alzheimer's disease diagnosis or prefer not to be publicly identified with Alzheimer's disease.*

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Suggestions for further reading

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Bookmarks

The new and noteworthy titles listed below have recently crossed the Managing Editor's desk. We hope to publish reviews for many of these works in upcoming issues. In the meantime, if any of these titles pique your interest, consult your bookseller or librarian for more information.

Alzheimer's Disease and Related Disorders Annual edited by Serge Gauthier, MD, and Jeffrey Cummings, MD (London: Martin Dunitz Publishers, 2000).

Assessing Quality of Life in Alzheimer's Disease edited by Steven M. Albert, PhD, MSc, and Rebecca G. Logsdon, PhD (New York: Springer, 2000).

Can Do Activities for Adults with Alzheimer's Disease: Strength-Based Communication and Programming by Eileen Eisner, CCC, SLP (Austin, TX: Pro-Ed, Inc., 2001).

Comforting the Confused: Strategies for Managing Dementia, 3rd Ed., by Stephanie B. Hoffman, PhD, and Constance A. Platt, MA (New York: Springer, 2000).

Handbook on Dementia Caregiving: Evidence-Based Interventions for Family Caregivers edited by Richard Schultz, PhD (New York: Springer, 2000).

Interventions in Dementia Care: Toward Improving Quality of Life edited by M. Powell Lawton, PhD, and Robert L. Rubinstein, PhD (New York: Springer, 2000).

The Loss of Self: A Family Resource for the Care of Alzheimer's Disease and Related Dementias by Donna Cohen, PhD, and Carl Eisdorfer, PhD, MD (New York: W. W. Norton and Company, 2001).

The Moral Challenge of Alzheimer Disease: Ethical Issues from Diagnosis to Dying, 2nd Ed., by Stephen G. Post, PhD (Baltimore: Johns Hopkins University Press, 2000).

Moving a Relative with Memory Loss: A Family Caregiver's Guide by Laurie White and Beth Spencer (Santa Rosa, CA: Whisp Publications, 2001)

Parkinson's Disease: A Complete Guide for Patients and Families by William J. Weiner, MD, Lisa M. Shulman, MD, and Anthony E. Lang, MD, FRCP (Baltimore: Johns Hopkins University Press, 2001).

Through the Wilderness of Alzheimer's: A Guide in Two Voices by Robert and Anne Simpson (Minneapolis: Augsburg Fortress, 1999).