

Self-ratings of Everyday Memory Problems in Patients with Acquired Brain Injury - A Tool for Rehabilitation

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Abstract

Introduction: Memory problems are common in everyday life of patients with acquired brain injury (ABI). Some patients with ABI also have problems with self-monitoring/awareness. The ecological validity of neuropsychological tests for everyday life memory problems is questionable. Can self-report instruments supply complementary information?

Aims: 1) To document the frequency/impact of self-reported memory problems in a sample of consecutive referrals of ABI patients using PEEM and REEM. 2) To characterize the instruments with respect to psychometrics and internal consistency. 3) To document differences in memory problem patterns for various kinds/localization of brain lesions, and associated anxiety/ depression symptoms.

Methods: A descriptive retrospective study of consecutive referrals of ABI patients was performed. Ratings from the Evaluation of Everyday Memory (EEM), in a patient version (PEEM) and a version for relatives/proxies (REEM) were analysed as well as self-ratings of anxiety and depression.

Results: The EEM instruments displayed good psychometric characteristics. The mean PEEM score were close to the tenth percentile of healthy controls. PEEM and REEM versions were strongly inter-correlated. Sex, age, and lesion characteristics did not matter much with one exception. Right-hemisphere lesion patients rated their memory problems significantly lower than the proxy, for all other lesions it was vice versa. Anxiety and depression symptoms were associated with memory problems.

Keywords: Anosognosia; Anxiety; Brain injury; Clinical relevance; Daily life; Depression; Neuropsychology

Abbreviations

ABI: Aquired Brain Injury; EEM: Evaluation of Everyday Memory; CFQ: Cognitive Failures Questionnaire; EMQ: Everyday Memory Questionnaire

Introduction

Patients with mild acquired brain injury (ABI), i.e. patients with a level of cognitive functioning representing VII-X on the revised Rancho Los Amigos Levels of cognitive Functioning Scale -LOCF (http://www.neuroskills.com/resources/rancho-los-amigos-

revised.php) often suffer from cognitive consequences long time after their injury or disease. Self-reported difficulties are often described as impaired concentration and memory. Residual memory deficits are one of the most common consequences of ABI, which may impair an individual's memory performance in everyday life [1]. However, authentic memory deficits has been proven to be difficult to identify, at least to the point that everyday memory difficulties appear to display only weak associations with memory indices obtained by cognitive/

neuropsychological tests [2,3]. Several recent reviews have suggested that cognitive rehabilitation of memory can be most beneficial [4].

Memory reflects processes in at least five separate brain systems, with multiple connections to other systems/processes, including the Central Executive (CE) system. Most of the current knowledge of memory is laboratory-based, and refers to the nuts and bolts of the various sub-processes. This approach may over-look the ecological aspect associated with everyday memory [5], including the consequences for cognition, self-image and social life.

When planning and implementing rehabilitation interventions in patients with ABI it is important to identify the presence of every-day memory problems as well as the existence of poor self-awareness [6]. A person with an impaired self-awareness of memory functions, in isolation or as part of general CE dysfunction, may be unaware of the consequences and thus unable to decide whether, when and where he/she should use compensatory strategies or assistive techniques. In order to put together an optimal memory remediation program for the individual patient it would be helpful to gain more knowledge in various kinds of memory/self-awareness problems related to the brain lesion, e.g. site, extension, cause and time aspects.

Anosognosia is an extreme form of poor self-awareness, particularly in the form of neglect with respect to a right-hemisphere lesion causing left-arm paresis. [7]. It is conceivable that there are milder forms, which still are of a magnitude that is clinically significant. Such problems are often referred to as caused by frontal lesions and a consequent CE dysfunction [8], but the literature is inconclusive. Theoretically, the right hemisphere processing mode, global/image/ non-verbally oriented rather than sequential and verbal, may be an essential component of self-monitoring processes.

Other phenomena following ABI are emotional problems. In a study by Silver, McAllister and Arciniegas [9] the authors report that posttraumatic depression, are present in between 10% and 80% of the cases in different studies. The risk of developing a depression remains elevated for decades after such an event. Additionally, even so called "well-recovered" individuals after ABI, who had sustained a minor trauma more than half a decade ago, were still found to suffer long-term cognitive and emotional consequences relevant for everyday social and professional life [3,10]. Self-report data on impairments in everyday life have also been found to be associated with anxiety and depression [11].

Everyday memory is a broad concept which could be referred to as ...memory operations that routinely occur in one's daily environment...The hallmark of everyday memory and associated research, then, is that it involves the performance of tasks that occur naturalistically in the real world. This is in contrast to typical laboratory tasks on memory, in which individuals may be asked to do things not typical of what they do in the real world (http:// medicine.jrank.org/pages/1136/Memory-Everyday.html).

Self-reported everyday memory has been evaluated by different questionnaires such as: Cognitive Failures Questionnaire-CFQ [12] and Everyday Memory Questionnaire-EMQ [13]. These questionnaires have also been used in different scientific studies, often together with neuropsychological tests. However, the relationship between performance on traditional neuropsychological memory tests and corresponding problems in everyday settings (ecological validity) has been found to be vague [14-16].

In a review by Herrman and Neisser [17] the authors identified 14 different memory questionnaires. The authors then proposed that self-report measures do not measure memory performance per se, but are measures of meta-memory, or beliefs about memory performance. They concluded that there are good arguments for using self-report memory questionnaires as well as other self-report instruments concerning for instance cognition in order to assess first-hand information among patients with psychiatric and neurological disorders. Recently, the validity of self-report instruments has been discussed with reference to schizophrenia: even when self-monitoring is compromised self-ratings are generally surprisingly valid [18].

In order to validate self-reported memory problems in everyday life there are two kinds of studies. In some studies self-ratings of memory functioning have been compared with ratings by proxies like close friends, family members and rehabilitation staff [6]. In other studies ABI patients are compared with controls. Patients with ABI report significantly more problems than their relatives report on a range of scales including everyday memory [3] and more problems than controls [10].

A valid and reliable everyday memory questionnaire has several uses in cognitive rehabilitation. It is an ecologically relevant tool to assess everyday memory as an adjunct to standard clinical tests. Thereby, a more comprehensive understanding of a patient's individual memory problem can be obtained. Adding proxy information concerning these problems makes it possible to tailormake appropriate clinical interventions. By sharing information among care-giver and care-taker, there is a basis for developing conjoint decision-making and hence to improve the therapeutic alliance [19].

In the present study we used data from a self-reported instrument "Evaluation of Everyday Memory" (EEM). Data have been collected as a clinical routine for out-patients and their proxies within the department for several years. The EEM is a modified instrument based on a mix of questions from two well-known instruments, EMQ and CFQ together with some additional questions in order to match the problems relevant for this specific patient group. There is a patient version (PEEM) and an almost identical version for relatives/proxies (REEM).

Aims

(1) To document the frequency/impact of self-reported memory problems in a sample of consecutive referrals of ABI patients using PEEM and REEM. (2) To characterize the instruments with respect to psychometrics and internal consistency. (3) To document differences in memory problem patterns for various kinds/localization of brain lesions, and associated anxiety/ depression symptoms.

Method

This study is a retrospective analysis of a consecutive sample collected over seven years at a unit for rehabilitation of ABI outpatients.

Participants

The criteria for inclusion of patients in the analyses were:

- Diagnosed as having remaining cognitive dysfunction due to ABI.
- Tested for cognitive function by a neuropsychologist.
- Being on Level VII-VIII on the Rancho Levels of Cognitive Functioning at the time of intervention [20].
- Over the age of 18.
- Having filled in the EEM (patient and/or relative version)

The analyses of the patients were based on 124 men with a mean age of 48 y and 71 women, mean age 46 y. For information on participants main diagnose and location of injury see Tables 1 and 2.

Instruments

The Evaluation of Everyday Memory (EEM) was compiled from a set of candidate items in order to match the special consequences in everyday life for adult patients suffering from remaining cognitive dysfunction due to a mild or moderate ABI. There is a patient version (PEEM) and a version for relatives/proxies (REEM). The PEEM and REEM were based on the EMQ [13] and the Cognitive Failure Scale CFQ [12], which are commonly used instruments to assess everyday memory problems. The original version of EEM distributed to patients and their relatives/proxies in this study includes 22 questions on everyday memory problems. Six of the 22 questions are included in both the EMQ and CFQ. Seven questions are included in EMQ only and two questions in CFQ only. The content in the seven remaining questions are similar to some of the remaining questions in EMQ or CFQ, but not identical. The respondent is asked about how frequently the specific memory problems occur for the patient. The response

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alternatives are identical to the ones used in the CFQ (range 0 to 4): Never, Rarely, Occasionally, Quite often, Very often.

The Hospital Anxiety and Depression Scale -HAD, [21] has been found to be a reliable instrument for assessment of depression and anxiety in the setting of an outpatient clinic. The HAD includes 14 questions, seven related to anxiety and seven related to depression. The patient answers each question on a four-point graded scale referring to the last week; 0 = not at all and 3 = definitely. Sums are computed for the two subscales and can range from 0-21. Sums up to 7 suggest that there are no relevant symptoms, 8-10 that some symptoms are present; scores > 11 suggest that the patient suffers from a clinically relevant depression and/or anxiety disorder [22].

Procedure

All data were collected retrospectively as part of the quality control program of the clinic. At follow-up, data from clinical protocols and medical records for consecutive patients between January 2005 and December 2011 were entered into a separate database, which was then deidentified. Among the data, information on demography and clinical data regarding the brain lesion were included.

Statistical methods

Standard statistical methods from the SPSS 22 package were used. After the initial analyses of the separate EEM items, missing values in the EEM scales were imputed based on linear regression analyses with all complete EEM variables as predictors. Reliability analyses including analyses of the homogeneity were conducted on the EEM scales. Main and interaction effects of background and clinical variables were analyzed by t-tests, ANOVAs and correlation analyses with a p < .05 considered significant. Spearman's rank correlation coefficient was used to study the relation between the PEEM and REEM scales.

Ethical Considerations

The study has been approved by the local Ethic committee in Linköping Dnr 2014/202-31. All data have been anonymized before any analyses have been undertaken. No single patient could be identified in the presented results.

Results

PEEM data were available for 168 of the 195 patients. REEM data were obtained for 89 patients. Matched PEEM and REEM data were available in 62 of the patients. HAD data were available for 158 of the 195 patients.

Patient EEM (PEEM)

The 22 memory items are presented in Table 3. A preliminary analysis suggested that Item 19 had a much skewed response distribution, 85% scored 0. A homogeneity analysis resulted in a very high Cronbach's alpha value (0.95), but Item 19 displayed a substantially lower correlation with the scale. Consequently, we decided to remove Item 19 in the final version, also because it has no specific theoretical relevance, neither any face validity (Appendix 1). The homogeneity of the 21 remaining items did not change (alpha = 0.95, single item intra-class correlation coefficient (iccc) was 0.47). A mean value PEEM is then a good estimate. This mean was 1.53 ± 0.81 . The distribution was slightly negatively skewed (Figure 1).

Diagnosis	n
Stroke	69
Subarachnoid hemorrhage	16
Infection	17
Trauma	56
Tumor	18
Other (e.g. anoxia)	19
Total	195

 Table 1: Summary of diagnoses based on information from patients'

 medical records (n= 195).

Localisation	Trauma n = 56			Non-trauma n = 139			Su m
	Bleeding	Infarction	Other	Bleeding	Infarction	Other	
Right	1	2	1	10	24	4	42
Left	0	1	0	5	22	6	34
Both	3	1	1	3	2	27	37
Frontal	5	0	6	3	1	10	25
Subcortical	0	0	0	1	6	3	10
Unspecified	25	0	10	2	3	7	47
Sum	34	4	18	24	58	57	195





The items differed with respect to the percentage of the participants who reported substantial problems here defined as a score of 2 or higher. These percentages are also presented in Table 3. Item 13 and 19 differed by a low rate of reported problems (fewer than 20%), Items for which substantial problems were reported quite often were 1, 3 and 17 (more than 70%).

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Item	PEEM (total n=168)			REEM (total n=89)			(total n=62)
	n	Score 2-4	Corr item vs. mean	n	Score 2-4	Corr item vs. mean	Corr PEEM vs. REEM
1. Do you forget where you have put something? Losing things around the house	165	71%	0.78	83	66%	0.66	0.46
Do you find you can't quite remember something although it's "on the tip of your tongue"?	166	65%	0.72	87	56%	0.61	0.56
3. Do you forget something you were told yesterday or a few days ago and have to be remembered?	167	71%	0.78	89	70%	0.71	0.34
4. Do you forget what you have just said. unable to "pick up the thread again"?	166	50%	0.76	86	35%	0.74	0.44
5. Do you forget when something happened. e.g. if it was yesterday or last week?	167	62%	0.69	88	58%	0.80	0.52
6. Do you forget to tell somebody something important? Perhaps forgetting to tell someone that some person has phoned?	165	49%	0.68	86	65%	0.71	0.44
7. Do you forget the names of friends or relatives or call them by the wrong names?	167	24%	0.63	88	14%	0.60	0.60
8. Do you have to go around checking whether you have done everything you meant to do?	165	64%	0.78	78	49%	0.77	0.68
9. Do you forget what the sentence you have just read was about and have to read it again?	165	61%	0.75	63	48%	0.78	0.50
10. Do you find you forget why you went from one part of the house to the other, and what you are supposed to do there?	165	49%	0.74	82	29%	0.80	0.50
11. Do you forget the names of common things?	166	27%	0.64	88	22%	0.64	0.32
12. Do you mix-up what different persons have been telling you?	161	42%	0.77	81	40%	0.78	0.27
13. Do you find it difficult to find the way in places you have often been to?	165	14%	0.66	88	8%	0.58	0.35
14. Do you leave important letters unanswered or forget to pay bills?	158	24%	0.64	76	20%	0.68	0.16
15. Do you forget to keep an appointment or agreement?	163	24%	0.69	82	22%	0.74	0.34
16. Do you forget to do things which you have promised or planned to do?	164	39%	0.76	84	43%	0.75	0.50
17. Do you have to write notes in order to remember?	163	80%	0.62	71	70%	0.65	0.59
18. Do other persons remind you that you are forgetting things?	157	46%	0.61	83	29%	0.69	0.40
19. Do you fail to recognize friends or relatives by sight?	165	7%	0.42	85	2%	0.27	0.33
20. Do you forget important phone-numbers or codes	163	29%	0.60	86	16%	0.57	0.33
21. Do you lose track of what someone is trying to tell you? Unable to follow the thread?	160	48%	0.74	80	29%	0.67	0.23
22. Do you get disturbed by others talking, when you are reading or watching TV?	165	67%	0.61	74	66%	0.48	0.55

Table 3: EEM items, percentage of patients and relatives who reported frequent memory problems (score 2, 3 or 4), correlations between each item and the scale mean for patients and relatives and correlations between patient and relative scores.

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Relatives/proxy EEM (REEM)

More or less complete data were obtained from 89 relatives/proxies. For items 9, 14, 17 and 22 there were many missing values, see Table 3. Item 19 had almost no variance.

Based on that, we decided to exclude these items in the final REEM version (Appendix 2). The following analyses are thus based on 17 items. A homogeneity analysis of these items resulted in alpha=0.94 and single item iccc=0.47. Consequently, the mean of these 17 items is a good estimate of memory problems. This mean was 1.20 ± 0.75 ; the distribution is shown in Figure 2.



Figure 2: Distribution of REEM (17 items) mean scores. n=89, Mean=1.20, SD=0.754.

According to the relatives, items for which substantial problems were reported quite often were 1, 3 and 6, of which the first two corresponds to the patients' view of their most common problems, see Table 3.

Correlations between PEEM and REEM

Comparing the mean PEEM (based on 21 items) with the mean REEM (based on 17 items) for the 62 patients with combined PEEM and REEM scores suggested that the relatives estimated the problems to be smaller than the patients did (PEEM= 1.34 ± 0.78 ; REEM= 0.99 ± 0.64 ; t(61)=4.32; p<0.001). This difference remained but was slightly smaller when comparing the mean REEM with the mean based on the 17 PEEM items that correspond to the REEM items (PEEM_ $17=1.27 \pm 0.79$; t(61=3.47, p<0.001).

The correlation between mean PEEM and mean REEM was 0.61 (Figure 3). As displayed in Table 3, Items 12, and 21 had the lowest correlation between PEEM and REEM items (less than 0.30, Spearman 's rank correlation coefficient). The correlation between the percentages of patients reporting substantial memory problems item for item and the corresponding percentages for relatives was high (tau(16)=0.75). Thus, patients and proxies actually agreed more when problems were labeled as low or high.

Diagnosis and localization

Table 2 displays the total number of patients in the present study (i.e. with PEEM or REEM data), their diagnoses and brain injury localizations. The Non-trauma / Other are patients mostly diagnosed with tumors, infection or anoxia.

EEM and effects of sex, age, and brain lesion characteristics

A number of analyses were conducted to study effects of demographic and clinical variables on the variance in PEEM and REEM. A third variable, the difference between PEEM and REEM was constructed to study the relation between the scoring of the patient and their relatives. Sex did not have any direct effect on any of the PEEM, REEM or PEEM-REEM variables. Patient age was positively correlated with REEM, r(87)=0.26, p<0.05, but had no effect on the other scores. Analyses of the effects of localization of the brain injury on the EEM variables suggested that there were differences in the PEEM scores among the localization-groups, F(5,162)=2.67, p<0.05. Patients with right-sided lesions scored lower and those coded as, unspecified localization scored higher. A t-test comparing patients with right-sided lesions with all others (performed for theoretical and statistical reasons) was significant for PEEM (t(166)=3.29, p<0.01) and PEEM-REEM (t(60)=2.26, p<0.05) and marginally significant for REEM (t(87)=1.96, p=0.053). Those with right-sided lesions scored lower than their proxy, for all other localizations it was the other way around. The PEEM-REEM variable confirms this pattern. This effect was large as assessed by Cohen's d: 0.84. These outcomes (localization effects on the EEM variables) did not change when controlling for age. Figure 3 displays a cross-tabulation of PEEM and REEM scores for the right-sided and all other patients.



Figure 3: Correlation between PEEM and REEM mean scores for right-sided location patients (red X, n=12) and all other patients (green circles, n=50).

A three-way ANOVA with PEEM scored as the dependent variable and with Trauma, Infarct/Bleeding/Other (Table 2) and sex as independent variables, and age as covariate was non-significant, i.e., none of these variables or combination of variables had any impact on the self-reported memory problems. The same analysis for REEM scores yielded one significant outcome, age was positively correlated with the REEM score, F(1, 77)=7.56, p<0.01, see above. The corresponding analysis with PEEM-REEM as the dependent variable did not yield any significant outcomes.

Association of EEM scores with anxiety and depressive symptoms

The mean Hospital Anxiety and Depression scores were 7.42 ± 4.34 and 5.90 ± 4.02 , respectively. The scores were strongly inter-correlated, r(156)=0.65, p<0.001. PEEM scores correlated positively and significantly with anxiety, r(151)=0.55, p<0.001, and with depression,

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r(151)=0.42, p<0.001. In contrast, REEM scores were un-correlated with anxiety/depression patient self-ratings.

On how to use the PEEM - Comparison Data Based on our Data Set

The PEEM and REEM questionnaires are supplemented with this report (Appendix 1 and 2). In addition to an inspection of the responses to the individual items, the mean PEEM score can be compared to our sample by calculation of a z score (which has a mean of 0 and a standard deviation of 1).

This is the algorithm: z=(x-1.53)/0.81.

A z-score of 0 is average relative to the current sample, a z-score above 0.5 is among the 31% with the most frequent everyday memory problems, a z-score above 1 is among the 16% with the most frequent everyday memory problems, and a z-score above 2 is among the 2.3% the most frequent everyday memory problems. A preliminary study using PEEM on the staff at a hospital unit (n=78) supports that the score at which memory problems start to become salient, defined as a score higher than that characterizing the top ten percent of the participants, can be set at 1.47, which corresponds to z=-0.07 among the patients. Thus, the mean PEEM score of the patients (1.53) is close to the tenth percentile of the preliminary healthy controls, and negative z scores are within the distribution of non-salient memory problems.

Discussion

The PEEM item analysis suggested that at least one item was deviant (20) and could be removed without consequences. The REEM item analysis showed that some items were difficult to assess for relatives - resulting in many missing values. Hence, the PEEM analyses are based on 21 items and the REEM analyses on a subset of 17 identical items. The EEM items (PEEM as well as REEM) displayed an unusually high homogeneity in spite of the fact that the items refer to quite different problems with widely varying reported frequencies. An un-weighted sum of the items is then a good estimate of the latent variable Everyday memory problems. The instrument would probably benefit by adding a summarized question and a Visual Analogue Scale (VAS) as the last item, asking "How much are you bothered by memory problems in your everyday life", similar to the 4S symptom self-rating scale for schizophrenia [19]. The internal consistency of the ratings of a specific patient can then be checked by comparing the PEEM sum-score with the VAS score.

The PEEM scores appear to be independent vs. age, sex, and most aspects of the diagnosis, with one exception. For patients with rightsided lesions their scores were lower than the others (less frequent problems), but their relatives assign them with higher scores (more frequent problems). This difference was highly significant, and large as assessed by Cohen's d statistic. It is well known in the literature that right-sided lesions are associated with neglect with respect to their leftsided motor deficits [7]. It appears that also the self-perception of memory problems, i.e., a more abstract concept than failure to execute a motor act, is affected by this problem. There are some notions on this in the literature, corroborating that an unbalance between the two hemispheres, the left one being much more active than the right, is linked not only with anosognosia but also poor self-monitoring/ insight [23-25]. This is clinically relevant when treating patients with right-hemisphere dysfunction [26,27]. Patient age was positively correlated with REEM. This finding might reflect that relatives observe and score more memory problems with increasing age. Another hypothesis is that younger patients more often have their partner as relative while older patients more often have their children; and that a partner tends to be more sensitive in their judgments compared to children.

The association between PEEM scores and anxiety/depression is not unexpected-however the causal aspect is more or less impossible to decipher: are memory problems the cause of anxiety/depression or is it the other way around, or is there a more general problem causing both? In any case, since anxiety and depressive problems are common and relevant for the memory ones, such problems should be assessed as a clinical routine in patients with brain lesions. Similar strong associations between anxiety/depression and neuro-cognitive problems have been repeatedly demonstrated in patients with Parkinson's disease [28].

A theoretically intriguing finding of the present study is that poor self-awareness of memory problems was quite strongly influenced by right-hemisphere lesions rather than by any other lesion localization. Frontal lesions are theoretically the most likely candidate, with reduced judgment and self-monitoring capacity mediated via the disruption of CE processing. The effects of such lesions were originally described by Rylander [29] and have since been verified repeatedly in the literature. In contrast, neglect is strongly linked to right hemisphere lesions. There are reports that other forms of anosognosia also may reflect right-sided lesions. Our findings bring this line of reasoning one step further - even a reduction of a rather nonconspicuous self-monitoring capacity which spontaneously is assumed to reflect a CE frontal dysfunction, seems to be exclusively righthemisphere based. If our findings are cross-validated it adds to the knowledge of the lateralization of the human brain and provides a new role for the right hemisphere, it will also have remedial/clinical consequences.

Conclusions

Summing up, the PEEM scale is a psychometrically sound, highly homogenous instrument, independent of sex, age and diagnoses (with one exception) and simple to use in the clinic as an instrument to assess memory problems in every-day life among patients with brain lesion. We suggest the following changes to the instrument: removal of item 19 and adding a VAS scale as the last item (Appendix 1). Then, the internal consistency of the ratings of an individual patient can be verified. The Relatives/proxy version of the EEM scale (REEM) should be modified by excluding five items (9, 14, 17, 19, 22) in order to improve the psychometric quality (Appendix 2). It should be noted that the PEEM and REEM scales can be used to verify effects of interventions, for instance memory training programs.

Study Limitations

Results from this study are based on clinical data including dropouts and missing values. This might have had an impact on results. However, this also means that data from all subjects being included in clinical interventions are used. Another limitation is the heterogeneity of the subject group which might have an impact on the validity since some of the subjects might have insight problems due to their brain dysfunction and therefor have given non-relevant responses to the questions. This however reflects clinical practice and has to be considered in subject's rehabilitation plans and interventions. The

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"healthy control" data are preliminary and therefore not presented in detail. More control data should be collected, as well as data for other diagnostic categories, like Parkinson's disease and early phases of other dementia disorders.

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