

Original Report

Assessing Dependency in a Multiethnic Community Cohort of Individuals With Alzheimer's Disease

Maria Meinerding, MS,^{1,2,3} Brittany DeFeis, MS,^{1,2,3} Preeti Sunderaraman, PhD,^{1,2,3} Martina Azar, BS,^{1,2,3,4} Siobhan Lawless, BS,^{1,2,3} Carlos Perez-Vivaldo, BA,^{1,2,3} Yian Gu, PhD,^{1,2,3} Yaakov Stern, PhD,^{1,2,3} and Stephanie Cosentino, PhD^{1,2,3,*}

¹Cognitive Neuroscience Division, Department of Neurology, ²G.H. Sergievsky Center and ³Taub Institute for Research on Alzheimer's Disease and The Aging Brain, Columbia University Medical Center, New York, New York. ⁴Department of Psychology, Drexel University, Philadelphia, Pennsylvania.

*Address correspondence to: Stephanie Cosentino, PhD, Columbia University Medical Center, 630 168th Street, P & S Box 16, New York, NY 10032.
E-mail: sc2460@cumc.columbia.edu

Received: August 22, 2017; Editorial Decision Date: April 3, 2018

Decision Editor: Laura P. Sands, PhD

Abstract

Background and Objectives: Clinic-based studies of patients with Alzheimer's disease (AD) have demonstrated the value of assessing dependence when characterizing patients' functional status. The Dependence Scale, a validated tool to assess level of caregiving needs, is associated with markers of disease severity, cost, and progression, while offering independent functional information about patients. This study examines whether such associations between the Dependence Scale and markers of disease severity demonstrated in clinical cohorts are similarly exhibited in a multiethnic community population of individuals with AD.

Research Design and Methods: One hundred fifty four elders with AD enrolled in the Predictors 3 cohort were assessed with the Dependence Scale, modified Mini-Mental State Examination (mMMS), instrumental (IADL) and basic (BADL) activities of daily living, and Clinical Dementia Rating (CDR) Scale, and were assigned an Equivalent Institutional Care (EIC) rating. Cross-sectional associations were examined using bivariate correlations and one-way analysis of variance analyses. Fisher-z tests examined differences in strengths of associations across previous clinic and current community cohorts.

Results: Dependence Scale scores were associated with CDR ($r = .20, p = .013$), mMMS ($r = -.23, p = .005$), IADL ($r = .39, p < .001$), BADL ($r = .65, p < .001$), and EIC ($r = .51, p < .001$). Dependence was unassociated with ethnicity ($F[3,144] = 1.027, p = .3822$), age ($r = .120, p = .145$), and education ($r = -.053, p = .519$). The strength of the correlations was comparable across cohorts except that BADLs were more strongly associated with dependence ($z = -4.60, p < .001$) in the community cohort, and living arrangement was not associated with dependence ($r = .13, p = .130$).

Discussion and Implications: Associations between the Dependence Scale and markers of disease severity in a clinic-based cohort of AD patients are similar to associations in a multiethnic community cohort of individuals diagnosed with AD. The Dependence Scale relates to markers of disease severity rather than demographic factors, and may offer an unbiased assessment of care required in multiethnic and community populations.

Translational significance: The Dependence Scale has similar associations with constructs of function and cognition in clinic and community cohorts of individuals with Alzheimer's disease. Dependence relates to markers of disease severity rather than demographic factors, and may offer an unbiased assessment of care required in multiethnic and community populations. Additionally, the scale offers unique information about an individual's need for institutional care among individuals in the community who are cared for in their homes.

Keywords: Alzheimer's disease, Caregiving, Cross-cultural issues, Dementia, Dependence

Increasing impairment in everyday functioning is a defining feature of Alzheimer's disease (AD) dementia (McKhann et al., 1984) and one which is inevitably linked to the dependence of the patient on family members or formal caregivers. Since its development, the Dependence Scale (Stern et al., 1994) has been used to directly assess the amount of assistance required by AD patients (e.g., *Does the patient need to be watched while at home?*). In addition to measuring the amount of care required by a patient with AD, the Dependence Scale provides an Equivalent Institutional Care (EIC) rating that represents the level of institutional care needed by a patient (Stern et al., 1994). The EIC rating is completed as the second part of the Dependence Scale, derived from both the Dependence Scale and an interviewer's holistic impression of patient care received regardless of the patient's actual living arrangement (e.g., in the home, skilled care facility, nursing home, etc.). The Dependence Scale thus offers unique information into the practical effects of AD not gained from other clinical instruments (Brickman et al., 2002).

The Dependence Scale was developed in the first cohort of the Predictors study (Predictors 1) (Stern et al., 1993), a longitudinal study designed to develop a predictor model of major outcomes in AD. Since its development, the Dependence Scale has been validated as a measure that is related to, but distinct from, existing cognitive, functional, and behavioral measures of disease (Lenderking et al., 2013). The Dependence Scale has been shown to be associated with cost in AD (Zhu et al., 2008) and to predict disease progression independent of other measures of functional and cognitive status (Brickman et al., 2002; Mortimer, Ebbitt, Jun, & Finch, 1992). Such associations, however, have been seen only in clinic-based and primarily Caucasian cohorts thus far. Given the notable differences in disease characteristics and outcomes that have been shown to exist across clinic-based samples and community-based samples (Alzheimer's Association, 2017; Farias, Mungas, Reed, Harvey, & DeCarli, 2009), it is important to determine the correlations of the Dependence Scale when implemented outside of the clinic and within a multiethnic cohort. Indeed, as the population of the United States shifts from a largely homogeneous Anglo-European society to a multicultural and multiracial society, it is important to assess the Dependence Scale in a community-based, multiethnic cohort.

The current study therefore aims to determine whether the Dependence Scale relates to markers of disease severity in a multiethnic community cohort of individuals with AD, and whether the strength of the associations is similar to that seen in a previous clinic cohort. This study also examined the extent to which Dependence Scale scores were associated with patient demographic characteristics and paid status of the caregiver in the community sample.

Results of this study will inform the use and value of the Dependence Scale outside of the clinic, both as a marker of disease severity and as a tool to provide unique information regarding an individual's functional status.

Methods

Participants

Predictors 1 clinical cohort

The longitudinal clinic-based Predictors study, design and cohort description published in 1993, was designed to predict the length of time to any major disease outcome in AD patients (Stern et al., 1993). Columbia University, Johns Hopkins University School of Medicine, and Massachusetts General Hospital screened approximately 345 individuals with probable AD. 232 individuals presenting with mild to prevalent dementia provided informed consent and were enrolled (Stern et al., 1994). Each participant met NINCDS-ADRDA criteria for mild to moderate probable AD (G. McKhann et al., 1984) defined by a score of ≥ 30 on the modified Mini-Mental State Examination (Stern, Sano, Paulson, & Mayeux, 1987), approximately equivalent to ≥ 16 on the Folstein Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975). Exclusion criteria included stroke, alcoholism, schizophrenia, schizoaffective disorder, and electroconvulsive treatments. Participants were required to speak English.

Predictors 3 community cohort and subset

Recruitment for the Predictors 3 community cohort (Stern et al., 2017) began in 2011, drawing from North Manhattan, NY residents enrolled in three waves of the Washington Heights-Hamilton Heights-Inwood Columbia Aging Project (WHICAP), beginning in 1992. Two hundred and seventy four individuals consented and enrolled in the Predictors study. Participants were required to speak English or Spanish. Individuals with incident and prevalent AD, as well as individuals at-risk for AD were recruited from WHICAP. Only incident and prevalent cases were included in the current study. Incident cases were identified as those who developed AD over the course of the WHICAP study. Prevalent cases were identified as WHICAP participants who met criteria for AD at their initial visit (Stern et al., 2017). 2011 Criterion for AD (McKhann et al., 2011) and at-risk for AD (Albert et al., 2011) were met. The current study examined 154 individuals for analysis.

Procedures and Measures

In addition to inclusion and exclusion criteria mentioned above, all individuals in the Predictors Study are required to have an informant in order to reduce participant burden

and provide a more-accurate assessment of patient abilities. Informants were identified as the individual who spent the greatest amount of time with the subject and was willing to participate. In the present study, informants are generally family members or home health aides. Informants who were nursing home staff are required to have worked with the individual for at least 3 months. Information about work, marital status, and living arrangement (e.g., living at home alone, at home with family, in a nursing home) of the participant was collected from the informant. Informants also provided their own ethnicity, gender, age, relationship to participant, years of education, hours spent with participant, whether or not they live with participant, and whether or not they are a paid caretaker.

Data from the current Predictors 3 sample were taken from each individual's baseline visit, at which time patients underwent cognitive testing and informants provided information regarding cognitive and functional symptoms of dementia. Baseline interviews were conducted by bilingual research staff, and were primarily completed in private homes (88.4%). The remainder of visits was completed at Columbia University Medical Center (10.2%), nursing homes (0.7%) and senior housing centers (0.7%). Informed consent was obtained from all participants and informants. As part of this process, research staff explained the study purpose, delineated the role of the informant and participant, and answered questions before obtaining consent from both the informant and the participant. As part of the consent process, research staff obtaining the consent evaluated the participant's capacity to provide informed consent (i.e., the participant's understanding of the study, risks and benefits, and the fact that participation is voluntary). For those participants who were deemed not to have the capacity to provide informed consent, a participant surrogate was required. Though informants may serve as a participant surrogate, surrogates were always a family member. Columbia University's Institutional Review Board approved the informed consent process. All interview questions were administered after consenting in the language preferred by the participant (English or Spanish). All instructions were previously translated into Spanish by a committee of Spanish speakers and then back-translated to ensure accuracy (Azar et al., 2017). Translations did not account for various Spanish dialects. Participants and informants each received a \$25 reimbursement at the end of their baseline visit.

The cognitive and functional assessments used to measure disease severity in the Predictors 1 clinical cohort were used for the Predictors 3 study. The scales used for analysis are detailed below.

Dependence Scale

The Dependence Scale (Stern et al., 1994) directly assesses the amount of assistance required by participants. This 13 question scale is administered to the patient's informant

by a bilingual research staff member. Items range from mild ("Does the patient need frequent help finding misplaced objects?") to severe ("Does the patient need to be tube fed?"), with low sum totals indicating less assistance required, to higher sums indicating a more advanced need of assistance from caregivers. A dependence level, ranging from 0 (totally independent), to 5 (totally dependent) is derived from the sum of the item scores ranging from 0 to 15. In this study, dependence levels were used for analysis, and are referred to as Dependence Scale scores.

Equivalent Institutional Care Rating

Based on the Dependence Scale interview with the informant, this rating is established from the second section of the Dependence Scale. The Equivalent Institutional Care rating is comprised of the interviewer's impression based on all information available regarding the actual level of care the patient is receiving, regardless of where the patient physically resides. A rating of 1 (limited home care), 2 (adult home—a supervised setting with regular assistance in most activities), or 3 (health-related facility) is assigned (Stern et al., 2017). The max level of 3 indicates the highest level of care the patient is receiving.

Modified Mini-Mental State Examination (mMMS)

This modified Folstein Mini-Mental State Examination (mMMS) was used to examine intellectual and cognitive function (Stern et al., 1987). This 57-point modification adds naming, registration, general knowledge, and additional attention and calculation items, with lower scores indicating poorer cognitive function. The current study examined total mMMS scores, with a possible range of 0–57. Higher scores indicate higher cognitive function.

Blessed Dementia Rating Scale

The Blessed Dementia Rating Scale (BDRS) was used to rate functional capacity (Blessed, Tomlimon, & Roth, 1967). A previously reported factor analysis of this scale identified four independent factors: cognitive impairment, self-care needs, personality disturbance, and apathy (Stern, Hesdorffer, Sano, & Mayeux, 1990). In the Predictors 1 clinical study (Stern et al., 1994), Dependence Scale scores and BDRS self-care scores were found to be related but distinct components of disability in AD. In the Predictors 3 community study, Basic Activities of Daily Living (BADL) and Instrumental Activities of Daily Living (IADL) subscores were used, previously reported as BDRS Self-care and BDRS-Cognition, respectively.

BADL scores were assigned from a three-item assessment with total scores ranging from 0 to 9. Scoring for each item is on a four-point basis, from 0 indicating no trouble to 3 indicating severe impairment (e.g., *unable to dress*,

incontinent). IADL scores were assigned from a seven-item assessment with total scores ranging from 0 to 7. Scoring for each item is on a three-point basis, 0 indicating no trouble, 0.5 indicating some trouble, and 1 indicating a lot of/severe trouble. Higher scores indicate decreased levels of functional capacity.

Clinical Dementia Rating Scale

The Clinical Dementia Rating Scale (CDR) was used as a global assessment of the severity of dementia (Berg, 1988). Six domains are scored on a 5-point scale: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care, with total scores ranging from 0 to 18. A global score is assigned and used for analysis: normal (0), very mild dementia (0.5), mild dementia (1), moderate dementia (2), and severe dementia (3).

Analysis

Cross-sectional associations were examined using bivariate and partial correlations between the Dependence Scale and the various measures of disease severity discussed above. This study also examined the extent to which dependence was associated with demographic characteristics of the participant and the paid status of the informant. One-way analysis of variances examined Dependence Scale scores as the dependent variable, in relation to race and informant status as the independent variable (paid caregiver such as home health aid as opposed to unpaid caregiver such as child or spouse). Bivariate correlations examined Dependence Scale scores in relation to age and education. Fisher-z tests examined differences in the strength of associations between Dependence Scale scores and markers of disease severity in the Predictors 3 community cohort as compared with the size of the associations the Predictors 1 clinical cohort (Stern et al., 1993). Positive z-scores indicate a greater *R*-value in the previous clinic based cohort, whereas negative z-scores indicate a greater *R*-value in the current community based study.

Results

Demographic characteristics of the participant samples at baseline, Dependence Scale scores, and Equivalent Institutional Care ratings are summarized in Table 1. The Predictors 3 sample is primarily female (81.8%), and the mean age of participants is 85.5 years old (6.48 *SD*) with a mean education of 6.1 years (4.69 *SD*). The sample is racially heterogeneous, although primarily self-identified as Caribbean Hispanic (83.1% Hispanic, 11.7% Black, 4.5% White). At baseline, nearly 99% of the participants lived at home, with 32% living alone, and 68% living with a family member or other caregiver, compared to 92%

Table 1. Sample Characteristics

	Predictors 1 Clinical Cohort	Predictors 3 Community Subset
	<i>N</i> (%) or <i>M</i> (<i>SD</i>)	<i>N</i> (%) or <i>M</i> (<i>SD</i>)
Gender		
Female	139 (60%)	126 (82%)
Male	93 (40%)	28 (18%)
Age (<i>SD</i>)	73.1 (8.7)	85.5 (6.5)
Education, years (<i>SD</i>)	13.1 (3.7)	6.1 (4.7)
Ethnicity		
White	209 (90%)	7 (4.5%)
Black	14 (6%)	18 (11.7%)
Hispanic	8 (3%)	128 (83.1%)
Other	0 (0%)	1 (0.6%)
Dependence Level	2.24 (.77)	3.59 (1.34)
0	8 (3%)	6 (4.1%)
1	9 (4%)	2 (1.4%)
2	149 (64%)	20 (13.5%)
3	56 (24%)	43 (29.1%)
4	9 (5%)	25 (16.9%)
5	2 (1%)	52 (35.1%)
Equivalent Institutional Care	1.52 (0.65)	1.96 (0.67)
Limited Home care	131 (56%)	36 (24.5%)
Adult home	82 (35%)	81 (55.1%)
Health-Related Facility	20 (9%)	30 (20.4%)
mMMS, mean (<i>SD</i>)	37.74 (5.5)	29.05 (7.6)
CDR, mean (<i>SD</i>)	1.1 (0.3)	1.1 (0.4)
IADL, mean (<i>SD</i>)	3.0 (1.32)	3.6 (1.9)
BADL, mean (<i>SD</i>)	0.53 (0.9)	2.0 (2.1)
Living arrangement		
Alone at Home	38 (17.3%)	48 (32.4%)
Home with Family or Other Caregiver	165 (75.3%)	98 (66.2%)
Health Related Facility	16 (7.3%)	2 (1.4%)

Note: BADL = Basic activities of daily living; CDR = Clinical Dementia Rating; IADL = Instrumental activities of daily living; mMMS = Modified Mini-Mental State Examination.

of the previous clinical-cohort living at home, with 17% living alone.

Most of the informants providing information regarding patients' levels of dependence lived independently from the participant (74%). The majority of informants identified as home health aides (55%). Children (24%), spouses (10%), and other friends and family members (11%) accounted for the remainder. Seventy-three percent of the informants had daily contact with the patient; 25% weekly contact, and 2% of informants had contact several hours per month. Informants were primarily female (89%), Hispanic (86%), and had a mean education of 12.42 years (4.10 *SD*).

Dependence Scale scores were associated with each measure of disease severity (Table 2). Functional measures, IADL ($r = .39, p < .001$) and BADL ($r = .65, p < .001$), were positively associated with Dependence Scale scores, as was

Table 2. Correlations of Dependency

	Predictors 1 Clinical Cohort			Predictors 3 Community Subset		
	<i>r</i>	<i>p</i> -value	<i>N</i>	<i>R</i>	<i>p</i> -value	<i>N</i>
mMMS	-.27	<.001	233	-0.23	.005**	144
CDR	.34	<.001	233	.20	.013*	148
IADL	.38	<.001	191	.39	.000**	147
BADL	.26	<.001	191	.65	.000**	147
EIC	.58	<.001	233	.51	.000**	147
Living Arrangement	<i>N</i>	<.001	219	.13	.130	147

Note: BADL = Basic activities of daily living; CDR = Clinical Dementia Rating; EIC = Equivalent Institutional Care; IADL = Instrumental activities of daily living; mMMS = Modified Mini-Mental State Examination.

**Correlation is significant at the .01 level (two-tailed). *Correlation is significant at the .05 level (two-tailed).

global cognition, CDR ($r = .20, p = .013$) and EIC ($r = .51, p < .001$). Dependence Scale scores were inversely associated with mMMS ($r = -.231, p = .005$) (Table 2). When controlling for age and education, Dependence Scale scores remained associated with mMMS ($r = -.215, p = .010$).

Dependence Scale scores were related to paid informant status ($r = .208, p = .013$). Home health aid informants reported higher levels of patient dependency ($M = 3.84, SD = 1.05$) than family or other unpaid informants ($M = 3.29, SD = 1.53$) ($F[1,140] = 6.345, p = .013$). Between group analysis found no difference between Dependence Scale scores and participant ethnicity, ($F[3,144] = 1.027, p = .3822$) or informant ethnicity ($F[2,144] = 2.382, p = .096$). Dependence Scale scores were not associated with age ($r = .120, p = .145$) or education ($r = -.053, p = .519$) of the participant, or of the informant ($r = -.056, p = .515; r = -.005, p = .955$).

We also assessed the relationship between Dependence Scale scores and a patient’s living arrangement. Less than 2% of patients lived in a nursing home or skilled care facility ($n = 2$), compared to 7% of the Predictors 1 clinical cohort ($n = 16$). The relationship between Dependence Scale scores and living arrangement was not significant ($p = .130$), as it was in the Predictors 1 cohort. The strength of the bivariate associations between the Dependence Scale scores and markers of disease severity was comparable across Predictors 1 clinic-based and Predictors 3 community-based cohorts (Table 3) except that the correlation between the Dependence Scale scores and BDRS-BADL was stronger in the Predictors 3 cohort ($z = -4.60, p = .000$).

Discussion

Few studies have examined the utility of clinical instruments assessing AD in multiethnic community dwelling populations. We examined whether the associations between the Dependence Scale and markers of disease severity, demonstrated in clinical cohorts, are similarly exhibited in a multiethnic community population of individuals diagnosed with AD. Demographic and clinical differences in the Predictors 3 community cohort as compared to Predictors

Table 3. Comparison Across Cohorts: Fisher-Z Tests

	<i>Z</i>	<i>p</i> -value
mMMS	-0.40	.344
CDR	1.43	.076
IADL	-0.11	.456
BADL	-4.60	.000*
EIC	0.94	.174

Note: BADL = Basic activities of daily living; CDR = Clinical Dementia Rating; EIC = Equivalent Institutional Care; IADL = Instrumental activities of daily living; mMMS = Modified Mini-Mental State Examination.

*Correlation is significant at the .01 level (two-tailed).

1 clinical cohort, such as a higher mean age, lower educational attainment, higher baseline Dependence Scale scores and lower functional capacity, offer the opportunity to examine if the Dependence Scale has similar correlations among individuals with AD with divergent backgrounds and characteristics.

Findings from the Predictors 3 cohort showed that Dependence Scale scores were significantly associated with markers of disease severity, including function and cognition, such that need for care increased with lower levels of functional and cognitive abilities. Additionally, as demonstrated by Fischer’s z tests, Dependence Scale scores were similarly associated with disease severity outcomes in both the Predictors 1 and Predictors 3 cohorts; however, two differences did arise. First, Dependence Scale scores were linked more strongly with basic activities of daily living (BADL) in the Predictors 3 cohort than in the Predictors 1 cohort. This difference may be attributable to functional differences between cohorts, specifically, the higher number of people scoring in the very impaired range on the BADL measure in the community cohort. The lower BADL level is consistent with the higher Dependence Scale scores in this cohort, and could reflect a number of factors including more advanced disease, older age, and lower levels of education than in individuals drawn from the Predictors 1 clinical cohort.

A second difference across cohorts was the lack of association between Dependence Scale scores and living arrangement in the Predictors 3 cohort. Despite being older

and having a more severe need for care, the Predictors 3 cohort had fewer patients (>1%) in institutional care than the Predictors 1 cohort (7%). This difference likely reflects differences in practices across the cohorts, such as Hispanic family members being more likely to take on the role of informal caregiving in order to keep patients at home (Gallagher-Thompson, Solano, Coon, & Areal, 2003). As long-term care for aging adults is primarily provided outside of nursing homes by informal unpaid caregivers (Bercovitz et al., 2011), this difference may be indicative of a more representative community population. The Equivalent Institutional Care rating, therefore, particularly the “health-related facility” rating, has the potential to serve as a more useful functional outcome than institutional placement in multiethnic community samples.

Finally, our study examined the extent to which Dependence Scale scores were associated with characteristics of the participants and informants in the Predictors 3 cohort. Dependence Scale scores were not associated with participant or informant age, education, or ethnicity. As the Dependence Scale relates to markers of disease related impairment rather than demographic factors, it has the potential to offer an unbiased assessment of care required in multiethnic and community populations. With regard to the paid status of the informant, home health aides reported higher levels of patient dependence than did family and nonpaid informants. This likely reflects an accurate depiction of the higher need for care required by the participant when a family decides to employ a home health aide.

In sum, current findings confirm that associations of Dependence Scale scores with measures of disease severity are similar in clinic and community settings. In previously established clinical-cohorts, the Dependence Scale has been associated with future outcomes for individuals with AD (Brickman et al., 2002; Mortimer et al., 1992). Ongoing longitudinal evaluation in the Predictors 3 community cohort will determine if the Dependence Scale can predict patient needs across the course of AD disease progression among individuals in the community. This understanding would aid caregivers in predicting future duties and responsibilities to meet the progressing service needs of patients in ethnically diverse, community-based populations.

Funding

This study was supported by the National Institute on Aging (R01 AG007370).

Conflict of Interest

None reported.

References

- 2017 Alzheimer's disease facts and figures. (2017). *Alzheimer's & Dementia*, 13, 325–373. doi:10.1016/j.jalz.2017.02.001
- Albert, M. S., DeKosky, S. T., Dickson, D., Dubois, B., Feldman, H. H., Fox, N. C.,...Phelps, C. H. (2011). The diagnosis of mild cognitive impairment due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia*, 7, 270–279. doi:10.1016/j.jalz.2011.03.008
- Azar, M., Zhu, C., DeFeis, B., Gu, Y., Ornstein, K., Lawless, S., & Cosentino, S. (2017). Increased reporting accuracy of Alzheimer disease symptoms in Caribbean hispanic informants. *Alzheimer Disease and Associated Disorders*, 31, 328–334. doi:10.1097/WAD.0000000000000199
- Bercovitz, A., Moss, A., Sengupta, M., Y Park-Lee, E., Jones, A., & Harris-Kojetin, L. (2011). *An Overview of Home Health Aides: United States, 2007*. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/21688727>
- Berg, L. (1988). Clinical dementia rating (CDR). *Psychopharmacology Bulletin*, 24, 637–639. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/3249765>
- Blessed, G., Tomlimon, B. E., & Roth, M. (1967). The Relationship between quantitative measures of dementia and of degenerative changes in the cerebral grey matter of elderly subjects. *Proceedings of the Royal Society of Medicine*. doi:10.1192/bjp.114.512.797
- Brickman, A. M., Riba, A., Bell, K., Marder, K., Albert, M., Brandt, J., & Stern, Y. (2002). Longitudinal assessment of patient dependence in Alzheimer disease. *Archives of Neurology*, 59, 1304–1308. doi:10.1001/archneur.59.8.1304
- Farias, S. T., Mungas, D., Reed, B. R., Harvey, D., & DeCarli, C. (2009). Progression of mild cognitive impairment to dementia in clinic- vs community-based cohorts. *Archives of Neurology*, 66, 1151–1157. doi:10.1001/archneur.2009.106
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). “Mini-mental state”. A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189–198. doi:10.1016/0022-3956(75)90026-6
- Gallagher-Thompson, D., Solano, N., Coon, D., & Areal, P. (2003). Recruitment and retention of latino dementia family caregivers in intervention research: Issues to face, lessons to learn. *The Gerontologist*, 43, 45–51. doi:10.1093/geront/43.1.45
- Lenderking, W. R., Wyrwich, K. W., Stolar, M., Howard, K. A., Leibman, C., Buchanan, J.,...Stern, Y. (2013). Reliability, validity, and interpretation of the dependence scale in mild to moderately severe Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias*, 28, 738–749. doi:10.1177/1533317513504609
- McKhann, G., Drachman, D., Folstein, M., Katzman, R., Price, D., & Stadlan, E. M. (1984). Clinical diagnosis of Alzheimer's disease: Report of the NINCDS-ADRDA Work Group under the auspices of Department of Health and Human Services Task Force on Alzheimer's disease. *Neurology*, 34, 939–944. doi:10.1212/WNL.34.7.939
- McKhann, G. M., Knopman, D. S., Chertkow, H., Hyman, B. T., Jack, C. R. Jr, Kawas, C. H.,...Phelps, C. H. (2011). The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia*, 7, 263–269. doi:10.1016/j.jalz.2011.03.005

- Mortimer, J. A., Ebbitt, B., Jun, S. P., & Finch, M. D. (1992). Predictors of cognitive and functional progression in patients with probable Alzheimer's disease. *Neurology*, *42*, 1689–1696. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/1513455>
- Stern, Y., Albert, S. M., Sano, M., Richards, M., Miller, L., Folstein, M.,...Lafleche, G. (1994). Assessing patient dependence in Alzheimer's disease. *Journal of Gerontology*, *49*, M216–M222. doi:10.1093/geronj/49.5.M216
- Stern, Y., Folstein, M., Albert, M., Richards, M., Miller, L., Bylsma, F.,...Sano, M. (1993). Multicenter study of predictors of disease course in Alzheimer disease (the "predictors study"). I. Study design, cohort description, and intersite comparisons. *Alzheimer Disease and Associated Disorders*, *7*, 3–21. doi:10.7916/D8BK2QT6
- Stern, Y., Gu, Y., Cosentino, S., Azar, M., Lawless, S., & Tatarina, O. (2017). The Predictors study: Development and baseline characteristics of the Predictors 3 cohort. *Alzheimer's & Dementia*, *13*, 20–27. doi:10.1016/j.jalz.2016.04.004
- Stern, Y., Hesdorffer, D., Sano, M., & Mayeux, R. (1990). Measurement and prediction of functional capacity in Alzheimer's disease. *Neurology*, *40*, 8–14. doi:10.1212/WNL.40.1.8
- Stern, Y., Sano, M., Paulson, J., & Mayeux, R. (1987). Modified minimal state examination: validity and reliability. *Neurology*, *37*, 179. PubMed: 3808297; doi:10.1212/WNL.37.2.179
- Zhu, C. W., Leibman, C., McLaughlin, T., Scarmeas, N., Albert, M., Brandt, J.,...Stern, Y. (2008). The effects of patient function and dependence on costs of care in Alzheimer's disease. *Journal of the American Geriatrics Society*, *56*, 1497–1503. doi:10.1111/j.1532-5415.2008.01798.x