

Agreement between self reports and proxy reports of quality of life in epilepsy patients

R. D. Hays, B. G. Vickrey, B. P. Hermann, K. Perrine, J. Cramer, K. Meador, K. Spritzer and O. Devinsky

Social Policy Department, RAND, 1700 Main Street, Santa Monica, CA 90407–2138 (R. D. Hays, B. G. Vickrey, K. Spritzer); UCLA, Los Angeles, CA (R. D. Hays, B. G. Vickrey); Epi-Care Center, University of Tennessee, Memphis, TN (B. P. Hermann); New York University Hospital for Joint Diseases, New York, NY (K. Perrine, O. Devinsky); VA Medical Center, West Haven, CT (J. Cramer); Yale University School of Medicine, New Haven, CT (J. Cramer); Medical College of Georgia, Augusta, GA, USA (K. Meador)

Agreement between self reports and proxy reports of quality of life was examined in a sample of 292 patients with epilepsy and their designated proxies. Patients and proxies completed an 89-item Quality of Life Inventory (QOLIE-89), with the items rephrased for the proxy. Results reveal moderate correlations (product-moment r ranging from 0.29 to 0.56 for 17 multi-item scales) between self reports and proxy reports. Agreement was good for measures of function that are directly observable and relatively poor for more subjective measures. Mean scale scores were significantly different between patients and proxies for only five of 17 multi-item scales. Proxy respondents systematically reported better functioning than did patients in three scales assessing cognitive functioning (all $p < 0.001$). By contrast, patients reported more positive health perceptions and less seizure distress than proxies. Patient educational attainment correlated inversely with degree of disagreement between patient and proxy reports for six of the 17 QOL scales and for the overall score. In addition, proxy educational attainment correlated positively with agreement for four scales. This study indicates that for group level comparisons, proxy respondents can be substituted for adults with epilepsy having low to moderate seizure frequency. However, for individual level assessments proxies should be used with caution.

Key words: Epilepsy, proxy reports, quality of life, self reports.

Data collection was funded by an unrestricted educational grant from Wallace Laboratories. Preparation of this article was supported in part by RAND from its internal research funds. We thank Jim Tebow and Jacqueline Campbell for secretarial support. The opinions expressed are those of the authors and do not necessarily reflect the views of the sponsor, RAND, UCLA, or other institutions affiliated with this project. Requests for the QOLIE-89 should be directed to: Contracts Office, RAND, 1700 Main Street, Santa Monica, CA 90407–2138, USA.

The importance of the patient's subjective experience in evaluating the impact of chronic illness and associated treatments has recently been recognized.^{1,2} As a result, quality of life (QOL) assessment is increasingly incorporated into the medical therapy evaluation process. The commission of this special issue of *Quality of Life Research* reflects the significant role of QOL assessment in monitoring the progress of individuals with epilepsy.

QOL is defined by how well one is able to function and how one feels about their daily life (well-being). Because of the emphasis on the phenomenological experience of the individual, self reports are the primary method of assessing QOL. However, some people are unwilling or unable (e.g., cognitively impaired) to provide self report information, and bias in evaluating the impact of treatment on QOL may be introduced if these individuals are omitted from the analysis. In these situations, it may be necessary to obtain information from a third party (proxy) who knows the person well enough to provide accurate information. Comparing self reports with proxy reports is necessary to determine the feasibility and potential limitations of using proxies as a substitute when self report QOL data are unavailable.

This study examines agreement between self reports and proxy reports in a sample of respondents who participated in a project to develop a QOL instrument for patients with epilepsy.³ A nearly identical QOL inventory was administered to patients and proxies, with the items rephrased for the proxy and instructions stating that the questions should be answered in a way that the proxy believed best described the patient's circumstances.

Method

Sample

Data were collected from a cohort of 304 adult men ($n = 174$) and women ($n = 130$). The analytical sample of 292 patients (12 individuals with missing data were excluded from the analysis) was 57% female; 93% high school graduates; 48% married or living as married, 38% single, 14% divorced, separated or widowed. The average age was 36 years (range from 18 to 64 years). The proxy respondents were 63% female; 90% high school graduates; average age of 44 years (range from 15 to 82 years).

Patients were enrolled from 25 seizure clinics across the US. Most were comprehensive epilepsy centres, although several were hospital and medical school neurology clinics. Enrollment criteria limited the sample to: age 17–65 years; at least a 10th grade education and an ability to read English; seizure types consisting of complex partial seizures, simple partial seizures, generalized tonic-clonic seizures, absence seizures, or myoclonic seizures; no medication (other than antiepileptic drugs) with central nervous system effects; no neuropsychological testing within the last six months; and no craniotomy in the last 12 months. In addition, seizure severity was defined as none, low, moderate, or high based on specific criteria.³ The majority (83% of the sample) had a level of seizure severity in the low to moderate range over the preceding year.³ All patients were required to bring a relative, friend, or significant other person to the initial visit to complete the proxy questionnaire. The proxy was required to have contact with the respondent at least once a week.

Measures

The Quality of Life in Epilepsy Inventory (QOLIE)-89³ is an extension of a QOL instrument developed for epilepsy surgery patients, the ESI-55.⁴ The QOLIE-89 contains 17 multi-item scales (86 items plus single item measures of change in health, sexual relations, and overall health)* that assess physical, mental, and social health aspects of QOL. It also includes an overall score that is a weighted linear composite of the 17 scales.⁵ All scales are scored on a 0–100 scale, with higher scores representing better quality of life.

* Single item measures of sexual relations and change in health were added to the QOLIE-89 after this study was completed.

Analytic Strategy

For each scale we calculated the average absolute value of the difference between self- and proxy reports, and mean bias (patient–proxy report), as well as the standard deviation of differences to account for individual patient–proxy differences masked by analysis of means.⁶ Scatter bias was estimated by regressing the difference between patient and proxy reports against the means of the self- and proxy reports for each respondent.⁷

Product–moment correlations were computed between the 17 corresponding self- and proxy reported scales and the overall QOLIE-89 score. We also calculated intraclass correlations (one-way model) to capture absolute differences not represented by product–moment correlations.⁸ We evaluated the two methods of assessing QOL (17 scales) using multitrait–multimethod (MTMM) analysis of product–moment correlations.⁹ Reported are the average correlation between corresponding patient and proxy measures, the average off-diagonal correlation (correlations between measures of different aspects of QOL), and a count of statistically significant differences between correlations of corresponding patient and proxy measures compared with appropriate other correlations in the MTMM matrix.¹⁰

The relationship of differences between patient and proxy reports with patient and proxy characteristics was examined by regressing the absolute value of patient and proxy differences on the following variables: age, educational attainment and gender of patient and proxy, patient comorbidity, living arrangement, number of years the patient and proxy have known each other, number of days each week the proxy has contact with the patient, and number of hours each week the proxy helps the patient with tasks. For parsimony, we trimmed nonsignificant independent variables using forward stepwise regression models (one for each QOL dependent variable) with variables entered only if they had a significant ($p < 0.05$) association with the criterion. Because we are interested in the overall pattern of relations across dependent variables, we limit our interpretations to consistently significant effects (i.e., across multiple dependent variables). This approach protects against significant effects due simply to multiple comparisons.

Results

Seventy-eight percent of the proxies reported seeing or talking to the patient every day, 7% five or six days a week, 5% three or four days a week, and 10%

one or two days a week. Sixty-seven percent of the proxies lived in the same household as the patient. On average, proxies reported having known the patient for 20 years (range from one to 54 years).

Table 1 presents information on the central tendency, variability, and reliability of the 17 QOLIE-89 scales and the QOLIE-89 overall score. None of the scales exhibited problematic levels of floor or ceiling effects (scores clustering near the minimum or maximum).³ Internal consistency reliabilities¹¹ for the multi-item scales ranged from 0.75 to 0.92, surpassing the 0.70 standard for group-level comparisons.¹² The reliability of the overall score, estimated using Mosier's (1943) formula,¹³ was 0.97 for self report and 0.98 for proxy report. Test-retest product-moment correlations for the 17 HRQOL scales ranged from 0.62 to 0.86 for a time interval under 3 weeks. Test-retest correlations for the overall score were 0.88 for both self and proxy reports.

Agreement indices for self versus proxy reports of QOL are provided in Table 2. The mean of the absolute value of differences between patient and proxy ranged from 11 to 29 points on the 0–100 scales. Statistically significant mean differences between patients and proxies (mean bias) were observed for five of 17 QOL scales. For health perceptions ($p < 0.05$) and seizure distress ($p < 0.05$), the bias was in the direction of proxies reporting worse QOL than the patients. For the three measures of cognitive function (language, attention, memory; all $p < 0.001$) the bias was in the direction of proxies reporting better QOL (i.e., more intact cognitive abilities) than patients.

The distribution of difference scores is summarized by the standard deviation of differences in Table 2. These standard deviations translate into standard errors ranging from 1.06 (overall QOL) to 2.45 (role disability due to emotional problems). The range of observed differences (not shown) was wide, with the smallest range being from -54 to 50 for health perceptions. The overall QOLIE-89 score had the smallest standard deviation of difference.

Scatter bias was evident for only two of the scales, health perceptions ($p < 0.05$) and social support ($p < 0.05$). Greater differences were seen between self- and proxy reports for patients with worse health perception scores than for patients with better health perception scores. For social support, greater differences were seen between patient and proxy reports for patients with more social support, but the overall mean difference was not significant.

Product-moment correlations between proxy and patient reports for corresponding QOL scales ranged from 0.29 to 0.56 ($p < 0.05$), indicating a moderate

degree of association. Product-moment and intraclass correlations were similar (Table 2), because mean bias tended to be minimal. Differences between the product-moment and intraclass correlations were evident for only four of five scales that had significant mean bias. The overall QOLIE-89 score had the largest correlation between patient and proxy reports (product-moment correlation = 0.61; intraclass correlation = 0.60).

The MTMM product-moment correlation matrix for the 17 QOL scales is given in the Appendix. The average of the convergent validity correlations (correlations between patient and proxy reports for the same QOL scale) was 0.46, and the average of the off-diagonal correlations (correlations between different QOL scales) was 0.32. Although the convergent correlations were on average higher than the off-diagonal correlations, the difference was small. To provide a specific index of discriminant validity, we compared convergent validity correlations with appropriate off-diagonal correlations: t -tests of the difference between dependent correlations¹⁴ indicated that 673 out of 1088 correlations (61.9%) were statistically significant in a direction supporting the discriminant validity of the measures.

A summary of discriminant validity for each scale separately (percentage of statistically significant t -statistics) is provided in the final column of Table 2. The lowest level of discriminant validity was observed for role disability due to emotional problems (9%) and the highest level was obtained for the measures of physical functioning and pain (97%). Discriminant validity was also poor for role disability due to physical health, social support, emotional well-being, language cognitive function, medication effects, and health discouragement. Discriminant validity was good for health perceptions, memory cognitive function, seizure distress, and social functioning.

Separate stepwise regression models were run for each of the 17 QOL scales and the overall QOLIE-89 score to estimate the associations of patient and proxy characteristics with the absolute difference between patient and proxy reports. The most consistently significant effect ($p < 0.05$) was between patient educational attainment and less disagreement between patient and proxy reports. That is, for seven of the 18 regression models (physical functioning, pain, overall QOL, attention cognitive function, health discouragement, social function, and the overall QOLIE-89 score) there was better agreement between patient and proxy reports for patients with higher educational attainment. Similarly, proxy educational attainment was significantly positively associated with degree of agreement between patient and proxy reports for four

Table 1. Central tendency, variability, and reliability of self reports and proxy reports of quality of life

Measure	Number of items	Mean	Standard deviation	Reliability		
				Internal consistency	Test-retest	
					r	ICC*
Physical functioning	10					
Self report		85.50	19.81	0.89	0.77	0.76
Proxy report		85.31	19.78	0.90	0.78	0.77
Pain	2					
Self report		75.94	24.74	0.87	0.67	0.66
Proxy report		76.24	24.89	0.89	0.74	0.73
Health perceptions	6					
Self report		68.68	19.41	0.78	0.81	0.81
Proxy report		65.81	21.95	0.83	0.83	0.82
Role disability due to physical health	5					
Self report		67.98	34.76	0.81	0.62	0.62
Proxy report		71.30	35.05	0.85	0.69	0.68
Social support	4					
Self report		73.16	22.68	0.84	0.77	0.77
Proxy report		72.23	19.88	0.76	0.69	0.69
Emotional well-being	5					
Self report		67.75	19.04	0.83	0.73	0.73
Proxy report		69.02	18.79	0.84	0.73	0.72
Overall quality of life	2					
Self report		67.65	18.26	0.79	0.80	0.80
Proxy report		68.34	17.62	0.75	0.81	0.80
Social isolation	2					
Self report		77.33	24.49	0.88	0.70	0.69
Proxy report		77.81	22.17	0.87	0.69	0.68
Energy/fatigue	4					
Self report		55.84	20.86	0.84	0.71	0.71
Proxy report		54.04	21.52	0.87	0.76	0.76
Role disability due to emotional problems	5					
Self report		70.05	34.40	0.81	0.65	0.64
Proxy report		72.28	35.79	0.87	0.71	0.71
Language cognitive function	5					
Self report		74.72	21.00	0.88	0.73	0.72
Proxy report		80.73	20.95	0.89	0.73	0.72
Attention cognitive function	9					
Self report		70.33	20.75	0.92	0.85	0.85
Proxy report		76.35	19.66	0.91	0.82	0.81
Memory cognitive function	6					
Self report		54.15	24.06	0.88	0.83	0.83
Proxy report		65.99	25.36	0.91	0.83	0.83
Seizure distress/worry	5					
Self report		58.51	25.77	0.79	0.82	0.82
Proxy report		54.94	25.56	0.82	0.75	0.75
Medication effects	3					
Self report		55.95	30.52	0.78	0.65	0.65
Proxy report		55.79	27.64	0.76	0.62	0.61
Health discouragement	2					
Self report		70.07	27.71	0.82	0.71	0.70
Proxy report		68.73	27.25	0.86	0.72	0.71
Work/driving/socialfunction	11					
Self report		67.36	22.77	0.86	0.85	0.85
Proxy report		67.85	23.49	0.89	0.86	0.86
Overall QOLIE-89 score	86					
Self report		68.12	15.52	0.97**	0.88	0.87
Proxy report		69.72	16.42	0.98**	0.88	0.87

* One-way ANOVA model.

** Estimated using Mosier's (1943) formula.¹³

Table 2. Agreement between self reports and proxy reports

Measure	Mean absolute difference	Mean bias ^a	SD	Scatter bias <i>t</i> -ratio	<i>r</i>	ICC	Discriminant successes ^{***}
Physical functioning	10.61	0.19	18.78	0.02	0.55	0.55	7%
Pain	16.16	-0.30	23.33	-0.13	0.56	0.56	97%
Health perceptions	16.40	2.87*	20.11	-2.48*	0.53	0.52	83%
Role disability/physical	25.51	-3.32	36.72	-0.16	0.45	0.44	47%
Social support	18.82	0.93	24.48	2.40*	0.34	0.34	45%
Emotional well-being	15.42	-1.27	19.93	0.24	0.45	0.44	48%
Overall quality of life	13.85	-0.68	18.19	0.69	0.49	0.49	59%
Social isolation	17.12	-0.48	24.45	1.91	0.45	0.45	59%
Energy/fatigue	17.70	1.80	22.45	-0.59	0.44	0.44	58%
Role disability/emotional	29.01	-2.23	41.86	-0.71	0.29	0.29	9%
Language cognitive function	17.67	-6.01**	23.43	0.04	0.38	0.35	48%
Attention cognitive function	15.53	-6.01**	19.91	1.08	0.52	0.48	64%
Memory cognitive function	20.21	-11.84**	23.63	-1.07	0.54	0.46	91%
Seizure distress/worry	21.08	3.57*	26.93	0.16	0.45	0.44	78%
Medication effects	26.99	0.15	33.92	1.79	0.32	0.32	47%
Health discouragement	21.61	1.34	29.30	0.32	0.43	0.43	42%
Work/driving/social function	16.72	-0.49	21.65	-0.64	0.56	0.56	78%
Overall QOLIE-89 score	10.96	-1.59	14.19	-1.92	0.61	0.60	na

* $p < 0.05$; ** $p < 0.001$; SD = standard deviation of difference, r = product-moment, ICC = intraclass correlation.
^a Mean bias = patient score - proxy score; *** % statistically significant t -statistics.

QOL scales (physical functioning, social isolation, role limitations—emotional, language cognitive function).

Discussion

Our results reveal moderate correlations for self-reported QOL between patients with epilepsy and their designated proxies. The correlations reported here are somewhat lower than those reported for similar measures in a sample of 60 individuals over age 65 who received care or were eligible to receive care at the Harvard University Health Services and their proxies.¹⁵ For example, correlations of 0.53 for health perceptions and 0.45 for emotional well-being in this study are lower than correlations of 0.71 and 0.62, respectively, found by Epstein et al.¹⁵ The higher correspondence¹⁵ may in part be due to the selective nature of their sample, which consisted of faculty, staff, and administrative retirees from Harvard University. Our sample is less educated than this Harvard sample, and it is composed of individuals with a chronic illness who may have unique perceptions about QOL.

Mean scale scores for self and proxy reports were similar, with only five significant differences out of 17 scales. Nonetheless, correlations between proxy reports and patient reports were approximately as high for these five scales as the correlations observed for the other 12 QOLIE-89 scales. These mean differences

clustered in three scales assessing cognitive functioning, for which proxy respondents reported better functioning than did patients. Similarly, a study of community-dwelling older women found proxies to overrate cognitive functioning (measured by the Mental Status Questionnaire and Mini-Mental State Examination) relative to self reports.¹⁶ A previous analysis showed that the self-report cognitive functioning scales in the QOLIE-89 were weakly associated with neuropsychological performance scores after accounting for variance attributable to mood.¹⁷

In contrast to the cognitive functioning scales, patients reported more positive health perceptions and less seizure distress than proxies. These results are consistent with a study of 60 older individuals which showed that self ratings of emotional well-being were significantly higher than proxy ratings.¹⁵ Patients also rated themselves as less impaired physically than proxies rated them in a study of 275 veterans 40 to 103 years old.¹⁸ In general, proxies underreport the level of quality of life relative to self reports.¹⁹

Scatter bias was minimal, indicating that differences between proxy reports and self reports were generally unrelated to the patient's level of QOL except for health perceptions and social support scales. Proxies significantly underestimated health perceptions more for patients with poorer health than those with better health. Although the overall means were not significantly different for social support, scatter bias was

evident (i.e., patients reported significantly more social support relative to proxies at the higher end of social support, whereas proxies tended to overestimate the level of social support for patients at lower levels of social support).

Educational attainment was the only background characteristic that had consistently significant relationships with the level of agreement between patient and proxy reports. Higher educational attainment for patients and proxies was related to less disagreement between self-reported and proxy-reported QOL on several of the scales. These results are in accordance with previous research documenting lower data quality²⁰ and greater disagreement²¹ among individuals with less educational attainment. Agreement was also worse between self reports and proxy reports for respondents with cognitive impairment in another study.²²

The results of this study are based on a sample of individuals with a tenth grade education or higher and literacy in English. Thus, the results reported here are limited to these patients and may not apply to less literate and less healthy patients. Future research is needed to evaluate the generalizability of these results to other types of patients.

Degree of agreement between self reports and proxy reports was not consistently related to age or gender of patient or proxy, patient comorbidity, and familiarity of the proxy with the patient (living arrangement, number of years the patient and proxy have known each other, number of days each week the proxy has contact with the patient, number of hours each week the proxy helps the patient with tasks). Although prior research failed to show an association between age of patient and level of agreement, a positive association between familiarity of proxy with the target person and level of agreement has been suggested.^{21,23} The literature is inconclusive, however, as greater disagreement has been found for proxies who report spending more hours helping the target person.^{15,22} The patients and proxies in this study had frequent contact, most seeing one another at least once a week. The lack of variability in degree of contact may have prevented us from detecting an association between contact and level of agreement.

Consistent with previous research,^{1,15,16,18,22,24,25} we found that agreement was especially good for observable measures of function such as physical functioning and work/driving/social function. In contrast, agreement was relatively poor for the more subjective, internal perceptions such as emotional well-being, discouragement, and perceived social support. Agreement was particularly low for role disability due to

emotional problems. This scale requires respondents to attribute difficulties with their regular daily activities or work to their emotional problems (such as feeling depressed or anxious), an attribution that is difficult for proxies to make second-hand.

This study provides evidence about the extent to which proxy respondents can be substituted for patients in QOL studies. Average absolute differences between patient and proxy reports ranged from 11 (overall score) to 29 (role disability/emotional) on the 0–100 QOL scales.

For the majority of the scales, proxy respondents yielded mean scores that did not differ significantly from patient self reports, suggesting that use of proxies would not lead to bias for these scales. However, substituting proxies for patients would lead to substantially higher scores on average for the cognitive functioning scales (6–12 points). A 12 point difference is equivalent to the difference between epilepsy patients who experienced simple partial seizures (i.e., seizures without impairment of consciousness) compared to those patients who were seizure free during the preceding 12 months.⁴ Therefore, use of proxies could substantially bias results for these scales.

An integrated summary score was found to have very high reliability and was more valid than individual scale scores in HIV clinical trials.²⁶ In the current study, the QOLIE-89 overall score demonstrated the best reliability, the largest association between self and proxy reports, and the smallest standard deviation of difference, providing further support for the value of an integrated QOL score.

In summary, the results of this study indicate that proxy reports are moderately correlated with patient reports of QOL, agreement varies by QOL domain and educational attainment of both the patient and proxy, and bias in proxy responses is limited primarily to overestimating cognitive function (i.e., language, attention, memory). Thus, proxy data provide substantially different information than self reports for assessing the individual patient, but may provide a useful substitute for QOL at the group level. We recommend that proxy reports be used conservatively in sensitivity analyses to determine whether this imputation alters the conclusions of the study.

References

1. Guyatt GH, Feeny DH, Patrick DL. Measuring health-related quality of life. *Ann Intern Med* 1993; **118**: 622–629.
2. Stewart AL, Greenfield S, Hays RD, Wells K, Rogers WH, Berry SD, McGlynn EA, Ware JE. Functional status and well-being of patients with chronic condi-

- tions: Results from the Medical Outcomes Study. *JAMA* 1989; **262**: 907-913.
3. Devinsky O, Vickrey BG, Cramer J, Perrine K, Hermann B, Meador K, Hays RD. Development of the Quality of Life in Epilepsy (QOLIE) Inventory. Submitted for publication, June 1994.
 4. Vickrey B, Hays RD, Graber J, Rausch R, Engel J, Brook RH. A health-related quality of life instrument for patients evaluated for epilepsy surgery. *Med Care* 1992; **30**: 299-319.
 5. Vickrey B, Perrine K, Hays RD, Hermann B, Cramer J, Gordon J, Meador K, Devinsky O. *Scoring Manual for the Quality of Life in Epilepsy Inventory [QOLIE]-89*. Santa Monica, CA: RAND. 1993.
 6. Bland JM, Altman DG. Statistical methods for assessing agreement between two methods of clinical measurement. *Lancet* 1986; **8476**: 307-310.
 7. Marshall GN, Hays RD, Nicholas R. Evaluating agreement between clinical assessment methods. *Int J Methods Psychiatric Res* 1994; **4**: 249-257.
 8. Deyo RA, Diehr P, Patrick DL. Reproducibility and responsiveness of health status measures: Statistics and strategies for evaluation. *Controlled Clin Trials* 1991; **12**: 142S-158S.
 9. Campbell DT, Fiske DW. Convergent and discriminant validity by the multitrait-multimethod matrix. *Psychol Bull* 1959; **56**: 81-105.
 10. Hayashi T, Hays RD. A microcomputer program for analyzing multitrait-multimethod matrices. *Behav Res Methods, Instruments, Computers* 1987; **19**: 345-348.
 11. Cronbach LJ. Coefficient alpha and the internal structure of tests. *Psychometrika* 1951; **16**: 297-334.
 12. Nunnally JC. *Psychometric Theory*. New York: McGraw-Hill, 1978.
 13. Mosier CI. On the reliability of a weighted composite. *Psychometrika* 1943; **8**: 161-168.
 14. Steiger JH. Tests for comparing elements of a correlation matrix. *Psychol Bull* 1980; **87**: 245-251.
 15. Epstein AM, Hall JA, Tognetti J, Son LH, Conant L. Using proxies to evaluate quality of life: Can they provide valid information about patients' health status and satisfaction with medical care? *Med Care* 1989; **27**: S91-S98.
 16. Bassett SS, Magaziner J, Hebel JR. Reliability of proxy response on mental health indices for aged, community-dwelling women. *Psychol Aging* 1990; **5**: 127-132.
 17. Perrine K, Hermann BP, Meador KJ, Vickrey BG, Cramer JA, Hays RD, Devinsky O. The relationship of neuropsychological functioning to quality of life in epilepsy. *Arch Neurol*, in press.
 18. Rothman ML, Hedrick SC, Bulcroft KA, Hickam DH, Rubenstein LZ. The validity of proxy-generated scores as measures of patient health status. *Med Care* 1991; **29**: 115-124.
 19. Sprangers MAG, Aaronson NK. The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease: A review. *J Clin Epidemiol* 1992; **45**: 743-760.
 20. McHorney CA, Ware JE., Lu JFR, Sherbourne CD. The MOS 36-item short-form health survey (SF-36): III. Tests of data quality, scaling assumptions, and reliability across diverse patient groups. *Med Care* 1994; **32**: 40-66.
 21. McCusker J, Stoddard AM. Use of a surrogate for the Sickness Impact Profile. *Med Care* 1984; **22**: 789-795.
 22. Magaziner J, Simonsick EM, Kashner TM, Hebel JR. Patient-proxy response comparability on measures of patient health and functional status. *J Clin Epidemiol* 1988; **41**: 1065-1074.
 23. O'Brien J, Francis A. The use of next-of-kin to estimate pain in cancer patients. *Pain* 1988; **35**: 171-178.
 24. Herjanic B, Reich W. Development of a structured psychiatric interview for children: Agreement between child and parent on individual symptoms. *J Abnormal Child Psychol* 1982; **10**: 307-324.
 25. Kenrick DT, Stringfield DO. Personality traits and the eye of the beholder: Crossing some traditional philosophical boundaries in the search for consistency in all of the people. *Psychol Rev* 1980; **87**: 88-104.
 26. Bozzette SA, Hays RD, Berry S, Kanouse D. A perceived health index for use in persons with advanced HIV disease: Derivation, reliability, and validity. *Med Care* 1994; **32**: 716-731.

Appendix. Multitrait–Multimethod Product–Moment Correlations for 17 Scales (Decimals omitted)

	Self Report																
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Self Report																	
1. Physical functioning	100																
2. Pain	038	100															
3. Health perceptions	044	041	100														
4. Role disability/physical	030	049	037	100													
5. Social support	013	012	030	024	100												
6. Emotional well-being	023	026	042	040	051	100											
7. Overall quality of life	028	034	050	046	053	066	100										
8. Social isolation	008	018	024	033	048	057	047	100									
9. Energy/fatigue	027	031	046	045	042	059	053	035	100								
10. Role disability/emotional	020	025	029	052	029	059	046	047	042	100							
11. Language cognitive function	022	025	027	035	022	034	029	033	024	030	100						
12. Attention cognitive function	032	034	039	052	030	048	043	038	043	049	071	100					
13. Memory cognitive function	025	032	034	039	021	037	036	026	041	038	056	072	100				
14. Seizure distress/worry	010	022	027	023	013	034	026	027	024	025	022	029	029	100			
15. Medication effects	008	014	030	019	022	028	024	031	031	023	016	031	031	043	100		
16. Health discouragement	022	034	043	042	022	053	054	053	040	043	036	051	038	054	038	100	
17. Work/driving/social function	026	036	039	057	027	041	049	047	035	039	037	049	037	045	043	064	100

Appendix continued

Self Report

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Proxy Report																	
1. Physical functioning	(055)	035	031	031	007	017	021	004	024	016	018	024	028	007	000	015	025
2. Pain	030	(056)	027	036	007	020	028	018	023	023	019	029	030	010	011	023	023
3. Health perceptions	025	030	(053)	028	016	027	029	011	030	019	018	025	024	010	020	023	023
4. Role disability/physical	030	038	032	(045)	013	024	034	024	026	030	021	034	029	012	016	029	039
5. Social support	017	014	026	028	(034)	025	029	029	020	023	019	025	020	008	008	015	024
6. Emotional well-being	018	022	035	034	024	(044)	044	033	030	028	030	036	025	016	016	034	037
7. Overall quality of life	017	030	032	037	030	036	(049)	039	028	029	029	032	026	013	015	035	044
8. Social isolation	013	024	027	034	020	035	036	(045)	016	028	034	033	021	024	010	038	045
9. Energy/fatigue	023	022	037	032	021	024	031	018	(044)	021	017	028	028	014	025	027	034
10. Role disability/emotional	024	024	028	040	017	032	039	027	026	(029)	027	040	030	019	012	034	044
11. Language cognitive function	016	022	017	021	016	021	022	022	005	016	(038)	032	025	007	006	022	034
12. Attention cognitive function	022	024	026	038	022	028	033	028	019	026	043	(052)	042	021	013	034	046
13. Memory cognitive function	015	019	019	034	011	020	021	015	025	020	034	047	(054)	010	013	029	030
14. Seizure distress/worry	012	025	022	018	-002	022	017	015	018	013	021	020	018	(045)	022	035	036
15. Medication effects	004	019	016	018	-003	011	005	009	025	015	009	019	019	020	(032)	021	026
16. Health discouragement	024	021	030	029	009	031	030	025	020	019	030	033	027	033	019	(043)	046
17. Work/driving/social function	019	029	023	039	005	018	025	025	014	018	026	029	020	022	010	035	(056)

Appendix continued

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Proxy Report																	
1. Physical functioning	100																
2. Pain	043	100															
3. Health perceptions	042	044	100														
4. Role disability/physical	046	058	043	100													
5. Social support	020	018	038	039	100												
6. Emotional well-being	026	036	046	048	038	100											
7. Overall quality of life	034	043	045	054	046	064	100										
8. Social isolation	026	032	034	048	050	062	065	100									
9. Energy/fatigue	032	035	050	051	036	059	052	038	100								
10. Role disability/emotional	036	044	039	068	038	063	055	055	044	100							
11. Language cognitive function	034	023	033	036	022	033	039	041	026	034	100						
12. Attention cognitive function	043	035	041	053	037	046	053	055	045	054	069	100					
13. Memory cognitive function	035	034	041	042	019	036	039	033	042	035	053	067	100				
14. Seizure distress/worry	019	029	027	030	014	038	032	038	023	035	016	035	025	100			
15. Medication effects	016	024	031	029	015	029	028	028	027	031	018	027	030	046	100		
16. Health discouragement	035	029	039	050	029	059	049	057	043	060	035	055	038	063	034	100	
17. Work/driving/social function	038	041	037	058	034	053	063	066	042	060	046	060	043	049	041	065	100