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Assessing health-related quality of life in NeuroAIDS: Some psychometric properties of the Neurological Quality of Life Questionnaire (NeuroQOL)

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Abstract

Several studies were undertaken to assess the psychometric properties (reliability and initial convergent and discriminant construct validity) of the Neurological Quality of Life Questionnaire (NeuroQOL). The NeuroQOL contains 114 items answered in self report Likert format, with higher scores reflecting better quality of life. Study one compared the questionnaire with existing quality of life measures (Symptom Distress Scale, Sickness Impact Profile) and a significant ($p < 0.05$) correlation was found. Studies two through five evaluated the relationship between the NeuroQOL and disease stage, psychological, neuropsychological and neurological measures, and a significant correlation was also found with each domain. The internal consistency reliability (alpha = 0.96), split half reliability ($r_{12} = 0.97$), and test-retest reliability (coefficients were 0.78 for 6 months and 0.67 for one year intervals between test and retest) were all found to be high and adequately stable. Overall, these results indicate acceptable reliability and initial construct validity for the NeuroQOL.

Keywords: HIV; NeuroAids; Neurology; Neuropsychology; Quality of life; Reliability

1. Introduction

The primary goals of health care are to increase life expectancy and to improve well being (quality of life) throughout a person's life. Neurological illness may result in as limited means of expression, fatigue, and cognitive decline that make quality of life (QOL) assessment and judgment of treatment efficacy difficult.[1] Quality of life is an issue for multiple disorders including Parkinson's disease,[2–4] dementia,[5,6] Alzheimer's disease[7,8] and epilepsy.[9] As in other diseases, it is often the case that people with HIV do not wish to have life-prolonging measures taken unless this results in an adequate quality of life. The pathology, social stigma, and self-blame of people living with HIV/AIDS make patients more susceptible to depression symptoms as well as lower perceived QOL. The importance of QOL has been noted by many researchers and may be the most important outcome in progressive diseases such as HIV infection, where there is no current cure.[10]

Quality of life can be broadly defined as the subjective perception of life satisfaction and well-being, which includes the areas of bodily function and health status, psychological well-being, cognition, social interactions, self-care activities, and financial stability among others. Quality of life has important implications for health care in general

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and HIV infection in particular. However, there are important differences in the ways in which people view QOL. There are disagreements related to the subjective nature of people's descriptions of their QOL. Further, there are differences among health care professionals related to subjective QOL valuations of illness and injury, and health care.[11] Hence, it is of importance that health professionals find a reliable measure that does not ignore the patient's perspective on QOL.

Patients afflicted with HIV often exhibit neurologic,[12,13] neurocognitive,[14–18] and affective disorders such as depression and anxiety.[19] In fact, lower QOL scores have been found to be associated with a diagnosis of HIV and with disease-related symptoms.[20–23]

Quality of life related measures that are disease-specific require a greater level of emphasis upon the unique concerns of those affected by the relative disease. Although there are a number of QOL measures for high-prevalence conditions, there are fewer measures addressing the QOL of people with neurologic injury or disease. Since many QOL measures have not demonstrated sufficient validity, many examiners construct their own instruments. While this may proffer qualitative information, problems arise when attempts are made to validate these measures quantitatively. Given the fact that cognitively impaired HIV patients are less likely to employ effective strategies to manage stressors and in turn to alleviate symptoms of depression and anxiety,[24] it is important that there be a reliable QOL measure that provides a broad conceptual model taking into account domains beyond specific health-related aspects of HIV-related illness.

The Neurological Quality of Life Questionnaire (NeuroQOL) was developed to provide a measure of quality of life in HIV infection. The NeuroQOL was developed on a broad conceptual model taking into account domains beyond specific health-related aspects, and can utilize both unidimensional (overall summary score) and multidimensional (domain profiles) constructs. The present study reports the initial psychometric estimates (reliability and validity) of this instrument. Further, our goal was to assess whether the instrument significantly correlated with hypothetically similar constructs (convergent construct validity) and discriminant construct validity.

2. Method

The University of North Carolina Institutional Review Board approved the study, and all subjects gave informed consent for participation. Subjects were recruited and interviewed from June, 1991 to January, 1993. Subjects were administered the NeuroQOL by a clinical psychologist or trained nurse clinician as part of larger instrument protocols. All were either admitted as inpatients to the NIH General Clinical Research Center at the University of North Carolina (UNC) at Chapel Hill or interviewed at the UNC Infectious Disease clinic on an outpatient basis.

2.1. Subjects

Two separate subject samples participated in the five validity studies. The first sample participated in Study one. The first sample consisted of 63 subjects who were voluntary participants recruited from an infectious diseases clinic. Twenty-one subjects were asymptomatic (ASX, CDC II–III), 21 met criteria for AIDS-related complex (ARC, CDC IVA) and 21 met criteria for acquired immune deficiency syndrome (AIDS, CDC IVB-E). Subjects had a mean age of 33.92 years (range, 19–49, SD = 6.80) with a mean of 13.30 years of education (range, 2–23, SD = 3.14). Forty-three (68%) subjects were white, 18 (28%) were black, two (4%) were of other ethnic backgrounds. Fifty-four were male and nine were female.

The second sample participated in Studies two through five. The second sample consisted of 85 subjects who were voluntary participants in the AIDS Neurological Center longitudinal study. Fifteen subjects were high-risk HIV seronegative controls (CTRL), 32 subjects were asymptomatic (ASX, CDC II–III), 25 met criteria for AIDS-related complex (ARC, CDC IVA) and 13 met criteria for acquired immune deficiency syndrome (AIDS, CDC IVB-E). Subjects had a mean age of 35.97 years (range, 21–65, SD = 9.08) with a mean of 14.28 years of education (range, 5–22, SD = 2.91). Risk factors included homosexual contact in 73 (86%), exposure to blood products in four (5%), heterosexual contact in three (4%), and intravenous drug abuse in five (6%). Sixty-nine (81%) subjects were white, 13 (15%) were black, three (4%) were of other ethnic backgrounds. Eighty-one were male and four were female.

2.2. Procedure

At each evaluation, a neurologist conducted a quantified previously validated examination particularly sensitive to the neurological changes found in HIV disease. A neuropsychologist administered the NeuroQOL, and conducted detailed psychological and neuropsychological evaluations that have also been validated as sensitive to the neurocognitive changes found in HIV disease.

2.3. Instruments

The Neurological Quality of Life Questionnaire (NeuroQOL) is a self report instrument which assesses 11 domains: security, food, housing, financial, productivity, social support, relationships, psychological health, physical health, substance abuse, and cognitive/neurological problems. The NeuroQOL questionnaire contains 114 items answered in Likert format. The items are summed for a total score, with higher scores reflecting better quality of life.

The Sickness Impact Profile (SIP) is a self-report instrument with 136 items in 12 domains and summed into two dimensions: physical and psychosocial.[25]

The Symptom Distress Scale (SDS) is a self-report instrument with 13 items answered in a Likert format.[26]

The Brief Symptom Inventory (BSI)[27] is a self-report instrument measuring nine factors: somatization, obsessiveness, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism. Three global measures of psychological functioning are derived from the BSI: Positive Symptom Total, Positive Symptom Distress Index and the Global Severity Index.

The Profile of Mood States (POMS)[28] is a self-report instrument measuring six factors: tension, anger, depression, vigor, fatigue and confusion.

A complete standardized neurological history and clinical examination expanded from the AIDS Clinical Trials Group (ACTG) Full Neurologic Exam was utilized.

The neuropsychological battery assessed the areas of gross motor control, fine motor control, verbal recent memory, figural recent memory, concentration/speed of mental processing, initation/inhibition/mental flexibility, tactile perception, visuospatial/construction, and language. Individual test scores were externally standardized using z-scores based on normative data. The z-scores were derived from age and education-based norms available in the literature. Z-scores were summed within factors, and overall for a total score.

3. Results

3.1. Psychometric properties (reliability)

Full scale scores ranged from 184 to 435, with a mean of 339.18 (SD = 55.03) for the sample. Reliability coefficients, which set the upper limit on test validity, were computed.

The internal consistency reliability estimate for the full scale was high (alpha = 0.96). Table 1 presents the reliability coefficients, item total correlations and coefficients with the item removed for both raw and standardized variables. See Table 2 for reliability coefficients for the Quality of Life Domains.

Split half reliability was assessed using an 'odd-even' paradigm. All odd-numbered items were compared to all even-numbered items. Split half reliability was found to be high ($r_{12} = 0.97$).

Test-retest reliability for the full scale was estimated. Subjects were tested and a subset were then retested at 6 months ($n = 59$) and 1 year ($n = 39$). Test-retest reliability results indicated that the instrument has more than adequate stability over time. At 6 months between test and retest the coefficient was 0.78. At the 1 year interval between test and retest the coefficient was 0.67.

3.2. Psychometric properties (validity)

Study one (QOL measures): For the first sample ($n = 63$), NeuroQOL total scores ranged from 130 to 424, with a mean of 296.37 (SD = 62.95). The NeuroQOL total score was significantly (r [61] = −0.72, $p < 0.0001$) correlated with the Sickness Impact Profile total score. The NeuroQOL total score was significantly (r [61] = −0.79, $p < 0.0001$) correlated with the Symptom Distress Scale. The NeuroQOL total score was also significantly (r_s [61] = −0.44, $p < 0.0005$) correlated with the number of AIDS-related hospital admissions.

Study two (disease stage): For the second sample ($n = 85$), NeuroQOL total scores ranged from 184 to 435, with a mean of 339.18 (SD = 55.03). NeuroQOL total scores were significantly ($F_{3,84} = 14.21$, $p < 0.0001$) different across disease stage (CTRL = ASX > ARC > AIDS). The NeuroQOL domains significantly ($p < 0.001$) differing across disease stage were physical health, cognitive/neurological problems, psychological health, relationships, financial and productivity. NeuroQOL total scores were significantly (r [83] = 0.25, $p < .05$) correlated with absolute CD4+ cell counts. Table 3 contains results from comparisons of quality of life domains across HIV disease stages.

Study three (psychological): NeuroQOL total scores significantly (r [83] = −0.49 to −.060, $p < 0.0001$) correlated with the POMS factors of tension, depression, anger, vigor, fatigue, confusion. NeuroQOL total scores significantly (r [83] = −0.32 to −0.69, $p < 0.005$) correlated with the BSI factors of somatization, obsessive, interpersonal sensitivity, depression, anxiety, hostility, phobia, paranoid ideation, and psychoticism.

Study four (neuropsychological): NeuroQOL total scores significantly (r [83] = 0.48, $p < 0.0001$) correlated with the neuropsychological total z-score. The neuropsychological domains of gross motor control, fine motor control, verbal recent memory, concentration/speed of mental processing, initation/inhibition/mental flexibility were also significantly correlated with the NeuroQOL total score (r [83] = 0.33–0.46, $p < 0.005$).

Study five (neurological): NeuroQOL total scores significantly ($p < .05$) correlated with the ACTG full neurological exam summary scores. NeuroQOL was significantly correlated with overall dementia (r_s [83] = −0.26, $p < .05$), overall CNS motor dysfunction (r_s [83] = −.31, $p < .01$), overall peripheral neuropathy (r_s [83] = 0.38, $p < .001$), and AIDS dementia staging (r_s [83] = −0.41, $p < 0.0001$). Table 4 contains results from comparisons of quality of life with both the presence and the absence of neurological dysfunction.

4. Discussion

This paper assessed the psychometric properties of the Neurological Quality of Life Questionnaire (NeuroQOL), a general measure of quality of life in HIV infection. From the results of initial reliability analysis, it appears that the NeuroQOL is psychometrically sound and warrants consideration as an effective and reliable measure of the life satisfaction and subjective well-being of those with HIV infection.

According to Nunnally,[29] the upper limit for the reliability of tests is set by internal consistency reliability estimates. Acceptable reliability coefficients of internal consistency for instruments measuring constructs should

Table 1
Raw and standardized reliability coefficients for the full scale and by item

Domain	Question	Raw variables		Standard variables	
		Correlation with total	Alpha	Correlation with total	Alpha
Security					
	1. I feel safe where I live	0.21	0.96	0.21	0.96
	2. Crimes happen in my neighborhood	0.13	0.96	0.15	0.96
	3. I feel safe going out at night where I live	0.11	0.96	0.12	0.96
	4. I have to lock the doors where I live	−0.06	0.96	−0.05	0.96
	5. I know my needs will be met	0.44	0.96	0.44	0.96
Food					
	6. I have enough food to eat	0.34	0.96	0.33	0.96
	7. I usually have balanced meals	0.37	0.96	0.36	0.96
	8. I eat the right foods most of the time	0.33	0.96	0.32	0.96
	9. I can afford the food I need	0.40	0.96	0.39	0.96
Housing					
	10. I have my own place to stay	0.24	0.96	0.22	0.96
	11. It is crowded where I live	0.11	0.96	0.12	0.96
	12. It is always clean where I live	0.32	0.96	0.34	0.96
	13. The place where I live needs fixing up	0.28	0.96	0.30	0.96
	14. It is always warm enough in my home	0.35	0.96	0.35	0.96
	15. Sometimes it is too hot or cold in my house	0.31	0.96	0.31	0.96
	16. I live in a good place	0.33	0.96	0.33	0.96
	17. I have nowhere to live	0.02	0.96	0.04	0.96
Financial					
	18. I make enough money	0.45	0.96	0.41	0.96
	19. I have a good job	0.51	0.96	0.46	0.96
	20. I have enough to make ends meet	0.42	0.96	0.38	0.96
	21. I have to depend on other's support now	0.33	0.96	0.31	0.96
	22. I have enough to live on	0.43	0.96	0.41	0.96
	23. I have had a lot of training for my job	0.34	0.96	0.30	0.96
	24. I have adequate job security	0.48	0.96	0.45	0.96
	25. I have trouble paying my bills	0.30	0.96	0.30	0.96
Productivity					
	26. I can do as much as I used to	0.61	0.95	0.58	0.96
	27. I can get around as much as I used to	0.57	0.96	0.54	0.96
	28. I get tired easily now	0.42	0.96	0.42	0.96
	29. I am able to do all the things I want to	0.49	0.96	0.46	0.96
	30. I feel like I get things done	0.61	0.96	0.60	0.96
	31. I have to stay in bed a lot	0.67	0.95	0.67	0.96
	32. I have problems working	0.46	0.96	0.46	0.96
	33. I am as capable as I used to be	0.54	0.96	0.50	0.96
Social Support					
	34. I feel supported by others	0.32	0.96	0.30	0.96
	35. I have lots of friends	0.34	0.96	0.32	0.96
	36. I have people I can rely on	0.37	0.96	0.36	0.96
	37. Other people help me when I need it	0.39	0.96	0.38	0.96
	38. I feel I can depend on others	0.39	0.96	0.37	0.96
	39. I have family or friends who help me out	0.35	0.96	0.34	0.96
	40. I have been discriminated against	0.13	0.96	0.14	0.96
Relationships					
	41. I have others close to me	0.46	0.96	0.44	0.96
	42. I am close to my family	0.21	0.96	0.19	0.96
	43. I have a significant other	0.42	0.96	0.38	0.96
	44. I have many close friends	0.34	0.96	0.32	0.96
	45. I am in love with someone	0.32	0.96	0.28	0.96
	46. I have been interested in sex	0.32	0.96	0.27	0.96
	47. Sex has been important to me	0.24	0.96	0.20	0.96
	48. I could have gotten along without sex	0.25	0.96	0.23	0.96
	49. I feel lonely	0.52	0.96	0.53	0.96
	50. I have sex regularly	0.47	0.96	0.43	0.96
	51. My family and friends want to see me	0.30	0.96	0.28	0.96

(continued on next page)

Table 1 (*continued*)

Domain	Question	Raw variables		Standard variables	
		Correlation with total	Alpha	Correlation with total	Alpha
Psychological					
	52. I have had trouble sleeping	0.50	0.96	0.49	0.96
	53. I have been sleeping too much	0.49	0.96	0.51	0.96
	54. I have lost weight	0.43	0.96	0.42	0.96
	55. I have gained weight	0.22	0.96	0.22	0.96
	56. My appetite is fine	0.34	0.96	0.33	0.96
	57. I eat less now	0.29	0.96	0.29	0.96
	58. I have felt slowed down	0.56	0.96	0.55	0.96
	59. I have felt restless	0.48	0.96	0.51	0.96
	60. I have felt tired or unable to get things done	0.58	0.96	0.59	0.96
	61. I have felt worthless	0.53	0.96	0.56	0.96
	62. I have had trouble concentrating	0.58	0.96	0.61	0.96
	63. I have had trouble making decisions	0.57	0.96	0.59	0.96
	64. I have been crying more	0.31	0.96	0.35	0.96
	65. I have had thoughts about death	0.45	0.96	0.47	0.96
	66. I have thoughts of ending my life	0.37	0.96	0.40	0.96
	67. I have felt hopeless	0.49	0.96	0.52	0.96
	68. I have been nervous or worried	0.46	0.96	0.50	0.96
	69. I have been a little afraid	0.44	0.96	0.47	0.96
	70. I have been tense	0.31	0.96	0.35	0.96
	71. I have felt shaky	0.44	0.96	0.48	0.96
	72. I have had panic spells	0.29	0.96	0.32	0.96
	73. I have felt uneasy in crowds	0.44	0.96	0.47	0.96
	74. I have been suddenly scared for no reason	0.35	0.96	0.39	0.96
	75. I have been under some stress	0.20	0.96	0.23	0.96
	76. I have felt fatigued	0.57	0.96	0.57	0.96
	77. My stomach has been upset	0.41	0.96	0.43	0.96
Physical					
	78. I have been ill	0.58	0.96	0.59	0.96
	79. I have been feeling well	0.47	0.96	0.46	0.96
	80. I have had some infections	0.33	0.96	0.33	0.96
	81. I have had some pains	0.48	0.96	0.50	0.96
	82. I have had fevers	0.54	0.96	0.55	0.96
	83. I have had chills or night sweats	0.51	0.96	0.53	0.96
	84. I have been coughing	0.44	0.96	0.45	0.96
	85. I have had mouth infections	0.41	0.96	0.43	0.96
	86. I have had some trouble breathing	0.49	0.96	0.51	0.96
	87. I have had some blurry vision or eye problems	0.41	0.96	0.42	0.96
	89. I have had some diarrhea	0.48	0.96	0.51	0.96
	88. I have had some nausea or vomiting	0.50	0.96	0.53	0.96
	90. I have had skin rashes	0.39	0.96	0.40	0.96
	91. I have had some soreness	0.56	0.96	0.57	0.96
	92. I have to take a lot of medications	0.40	0.96	0.39	0.96
	93. I have to give up work due to my health	0.42	0.96	0.39	0.96
	94. I have trouble walking	0.44	0.96	0.43	0.96
Substance abuse					
	95. I have been drinking more than I should	0.11	0.96	0.13	0.96
	96. I have gotten into trouble while drinking or doing drugs	0.27	0.96	0.31	0.96
	97. I have used some drugs	0.35	0.96	0.37	0.96
	98. I have had problems with alcohol or drugs	0.08	0.96	0.10	0.96
	99. Others feel I have had problems with alcohol/drugs	0.18	0.96	0.21	0.96
	100. I have felt I needed to keep drinking or doing drugs	0.23	0.96	0.26	0.96
	101. I have been smoking	0.29	0.96	0.28	0.96
Cognitive					
	102. I have trouble paying attention to things	0.56	0.96	0.59	0.96
	103. I lose my train of thought	0.59	0.96	0.61	0.96
	104. I have trouble concentrating	0.59	0.96	0.61	0.96
	105. I have been confused	0.53	0.96	0.56	0.96
	106. I have had some memory lapses	0.55	0.96	0.56	0.96
	107. I am more forgetful	0.55	0.96	0.57	0.96
	108. I am slower than I used to be	0.65	0.95	0.65	0.96

Table 1 (*continued*)

Domain	Question	Raw variables		Standard variables	
		Correlation with total	Alpha	Correlation with total	Alpha
	109. I am as organized as I used to be	0.38	0.96	0.38	0.96
	110. I have had some trouble with coordination	0.56	0.96	0.57	0.96
	111. I have had some pain in my arms or legs	0.51	0.96	0.50	0.96
	112. I have numbness or tingling in my arms or legs	0.56	0.96	0.55	0.96
	113. I have had a change in my math abilities	0.41	0.96	0.42	0.96
	114. I am having some difficulties with household tasks	0.62	0.96	0.63	0.96

Note: Cronbach Coefficient Alpha for all raw variables = 0.96; Cronbach Coefficient Alpha for all standardized variables = 0.96.

Table 2
Reliability coefficients for the quality of life domains

DOMAIN	Raw	Standard
Security	0.581	0.598
Food	0.642	0.670
Housing	0.594	0.622
Financial	0.836	0.836
Productivity	0.885	0.886
Social support	0.867	0.874
Relationships	0.820	0.817
Physical health	0.922	0.928
Psychological health	0.902	0.906
Substance abuse	0.650	0.735
Cognitive/neurological	0.912	0.921

Table 3
Quality of life domains across HIV disease stage

NeuroQOL domains	CTRL	ASX	ARC	AIDS
Total*	384.33	356.56	323.84	286.69
Security	13.20	14.06	13.80	12.62
Food	13.46	12.00	11.88	10.69
Housing	26.93	26.47	25.88	25.14
Financial*	24.40	19.00	15.64	14.77
Productivity*	27.47	23.09	17.84	14.23
Social Support	20.87	21.28	19.84	19.08
Relationships*	31.87	29.72	27.68	20.85
Psychological health*	89.93	83.63	79.68	72.08
Physical health*	62.87	59.38	49.24	41.39
Substance abuse	26.13	24.81	23.56	25.23
Cognitive/neurological*	47.20	43.13	38.80	30.62

Note: CTRL = Control; ASX = Asymptomatic; ARC = AIDS related complex.
* (Significance at least $p < 0.001$).

Table 4
Quality of life scores by presence/absence of neurological dysfunction

Dysfunction	NeuroQOL total scores	
	Absent	Present
Dementia	343.05 (52.19)	275.80 (67.96)
CNS motor	344.15 (52.41)	290.13 (59.71)
Neuropathy	353.00 (51.59)	310.07 (51.29)
ADC	351.25 (49.33)	298.75 (54.92)

CNS = Central nervous system;
ADC = AIDS dementia complex.

fall in the modest range 0.50–0.60. However, a different standard is often applied for instruments that are used in settings where important decision-making or classification is based on the results, like IQ tests or measures that determine the course of and outcome of treatment. An instrument used in this manner should have full-scale reliability coefficients of internal consistency that are above 0.90. The internal consistency reliability coefficient for the NeuroQOL questionnaire was 0.96 and therefore above both of these standards. This suggests that the NeuroQOL questionnaire has relatively minimal levels of random error and a relatively homogenous sampling of items that appear to be measuring a similar attribute of quality of life.

Beyond a high level of internal consistency, the NeuroQOL also appears to have strong test-retest reliability. In order for a measure to represent the enduring status of a particular construct, like quality of life, it must remain relatively stable over time. In the absence of this stability, the validity of one's conclusions about this measure is more susceptible to measurement error and factors that are external to the test itself. For the NeuroQOL, the test-retest reliability coefficients were 0.78 and 0.67 after 6 and 12 months, respectively. This reflects high temporal stability, and the strength of these coefficients after such protracted periods of 6 and 12 months, compared to 2 weeks or 1 month, reduces the possibility that these findings are due to practice effects. Moreover, the relative disparity between these test-retest coefficients and the internal consistency coefficient suggests that this measure maintains temporal stability while retaining sensitivity to situational factors that may influence quality of life. Individuals who have HIV infection are highly susceptible to fluctuations in those factors that influence quality of life, like the ebb and flow of physical and cognitive symptoms, as well as vacillations in finances, relationships, and psychological factors. Therefore, the NeuroQOL appears to have high temporal stability while retaining an appropriate level of sensitivity to situational or circumstantial factors that may occur in the lives of those with HIV infection.

The studies presented in this paper also demonstrated adequate construct validity for the NeuroQOL questionnaire. Assessment of convergent construct validity revealed that the NeuroQOL correlated with two other quality of life instruments, the SIP and SDS, and with the number of AIDS-related hospital admissions. As discussed previously, health-related QOL measures a patient's perceived physical and mental well-being over time in order to gain insight into daily functional capacity. Because health-related quality of life pertains to a patient's "perceived"

well-being, consistently and reliably measuring quality of life is difficult, especially for neurologically impaired populations. The nature of neurological illness poses serious questions of reliably assessing quality of life. Whereas physically debilitating disorders may pose difficulties in actually filling out a self-report assessment, neurological deficits may affect a patient's ability to answer questions correctly. Despite these concerns, the NeuroQOL was found to directly correlate with SIP total scores, the SDS, and with the number of AIDS-related hospital admissions. In addition, according to Study five, the NeuroQOL was significantly correlated with overall dementia, overall CNS motor dysfunction, overall peripheral neuropathy, and AIDS dementia staging. These results indicate that the NeuroQOL is an effective tool in assessing quality of life in cognitively impaired neurological populations, at least prior to profound dementia.

Significant decreases in quality of life scores were found to be associated with advancing HIV disease stage and decreasing CD4+ cell counts. While health-centered measures focus mainly on verifiable physical health and daily function, person-centered measures reveal how the individuals themselves actually view their quality of life regardless of observable deficits. As patients adapt to disabilities (whether cognitive or physical in nature) perceived quality of life improves. Because of changes in coping skills and adaptation to disability, not all factors associated with quality of life change at the same rate. Specifically, in Study two, reported quality of life decreased with disease progression relative to overall total score and in relation to financial stability, productivity, relationships, psychological and physical health, and cognitive/neurological status.

Quality of life (NeuroQOL total scores) was found to decrease with increasing psychological distress. According to Study three, psychological factors directly affect the perceived quality of life of patients. QOL scores were found to correlate with symptoms of tension, depression, anger, vigor, fatigue, confusion, anxiety and hostility. This is a particularly important factor when assessing QOL in patients with HIV infection, as the pathology and social stigma associated with the disease leads to greater levels of depression and anxiety. Considering Murrell's suggestion,[1] discussed earlier, that a patient's values and perceptions of their normal abilities adapt as they become accustomed to disabilities, depressive symptoms may have a stronger impact than actual cognitive impairment on self-reported QOL. This would suggest that special attention should be placed on addressing psychological distress, anxiety and depression in the treatment of HIV infection.

Quality of life, as measured by the NeuroQOL, was found to decrease with increasing neuropsychological impairment. In Study four, the neuropsychological domains of gross motor control, fine motor control, verbal recent memory, concentration, processing speed, and executive functioning were significantly correlated with NeuroQOL total score.

Evidence of discriminant construct validity was also found in that NeuroQOL total scores were found to decrease as neurological dysfunction increased. NeuroQOL domains not expected to be related to measures of dysfunction (e.g. the NeuroQOL domains of security, housing, food, substance abuse) were not correlated with neurological dysfunction.

Although developed primarily for the assessment of subjective self-reports of neurocognitive and motor impairments that occur with HIV, the NeuroQOL appears to proffer an enhancement to current protocols (SIP, Nottingham Health Profile and SF-36) and disease-specific measures for other degenerative neurological disorders. Future studies may investigate the generalizability of the NeuroQOL for use with Parkinson's disease, vascular dementia, Alzheimer's disease, and epilepsy. Incorporation of the NeuroQOL into clinical trials in neurology may enhance QOL assessment. While current clinical trials may make use of QOL measures, these are usually as secondary outcome measures that do not adequately represent the full scope of the impact of disease on an individual with a chronic neurological disorder.

Overall, the NeuroQOL questionnaire appears to have high homogeneity and temporal stability. Quality of life has become increasingly important among those suffering from progressive diseases, like HIV infection. As many are living longer lives in the developed world with advanced antiretroviral treatment, concerns about maximizing life experience and well-being become paramount. However, in order to assess quality of life in these individuals, the field of health care and its practitioners need a reliable measure that can be used to determine the efficacy of interventions, inform treatment, and shape overall life satisfaction. From the foregoing results, the NeuroQOL appears to represent such a measure.

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