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Clinical study

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]