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Patient-Reported Outcome Measures in Huntington Disease: Neuro-QoL Social Functioning Measures

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Abstract

Social functioning is an essential but poorly understood component of health-related quality of life for people with Huntington disease. We report on the psychometric properties of two Neuro-QoL patient-reported outcome measures to assess social functioning in Huntington disease. Persons with prodromal (n=198) or manifest Huntington disease (n=195 early and n=117 late) completed Neuro-QoL Ability to Participate in Social Roles and Activities, and Satisfaction with Social Roles and Activities. Items from two generic health-related quality of life patient-reported outcome measures were used to create a social functioning composite score; items from the Unified Huntington's Disease Rating Scale and Problem Behaviors Assessment Scale were used to create a clinician-rated composite score of social function. Internal consistencies for the scores on the Neuro-QoL measures were excellent (> .88). Computer adaptive test administration had some advantages over computer-administered static Short Forms. Validity was supported by significant associations between the scores on the Neuro-QoL measures and other self- and clinician-reports of social function. Individuals with prodromal HD had better social functioning than the manifest HD groups; individuals with late-HD had less satisfaction and ability to participate in social roles and activities than the other two groups. Neuro-QoL provides brief, reliable scores of social functioning that measure ability to participate in, and satisfaction with, social roles and activities in persons with prodromal and manifest HD. In addition, test score interpretations of these measures support their validity in people with prodromal and manifest HD. These measurement tools add breadth to treatment outcome measures in HD and can increase understanding of the social implications of living with HD.

Keywords

Neuro-QoL; social participation; community integration; health-related quality of life; HDQLIFE; Huntington disease; prodromal; patient reported outcome (PRO)

Social activity and engagement have long been recognized as integral components of health (World Health Organization, 1946), but have received limited attention in clinical practice and research (Hahn, Cella, Bode, & Hanrahan, 2010; Hahn, Dewalt, Bode, Garcia, Devellis, Correia et al., 2014). The World Health Organization's International Classification of Functioning, Disability and Health has helped highlight social participation as both a determinant of health (Berkman, Glass, Brissette, & Seeman, 2000; Kamiya, Whelan, Timonen, & Kenny, 2010; Sundquist, Lindström, Malmström, Johansson, & Sundquist, 2004) and as a treatment outcome valued by patients, providers, and policy makers (Magasi, Hammel, Heinemann, Whiteneck, & Bogner, 2009). Given these factors, measures of social health will likely play a key role in clinical and research initiatives that emphasize how social activity and engagement influence health (Institute of Medicine, 2003, 2011; Whitehead, 1995).

Huntington disease (HD) is an autosomal-dominant, neurodegenerative condition which affects aspects of motor, cognitive and neuropsychiatric function essential for full participation in the activities of life. The neurodegenerative changes in HD affect physical, emotional, cognitive and behavioral functions that are important for interpersonal relationships, activities of daily living, work performance, and family responsibilities (Aubeeluck & Buchanan, 2006; Carlozzi & Tulsky, 2013; Coulson, Buchanan, & Aubeeluck, 2007; Hans & Koeppen, 1980; Kessler, 1993; Read, Jones, Owen, Leavitt, Coleman, Roos et al., 2013; Rothlind, Bylsma, Peyser, Folstein, & Brandt, 1993; Tyler, Harper, Davies, & Newcome, 1983; Vamos, Hambridge, Edwards, & Conaghan, 2007; Williams, Hamilton, Nehl, McGonigal-Kenney, Schutte, Sparbel et al., 2007). Therefore, social functioning is an important component of health-related quality of life (HRQOL) for people with HD. To date, very little research has focused on social functioning in HD. Furthermore, the field lacks patient-reported outcome (PRO) measures for assessing social functioning in HD. Scores on social functioning measures have potential importance as outcomes for clinical trials, yet no known study has provided validity data to support the clinical utility of HRQOL measures for social functioning either in treatment trials in people diagnosed with HD, nor in preventative trials in people in the premanifest stages of HD.

To this end, the Quality of Life in Neurological Disorders (Neuro-QoL) PRO measurement system was developed to assess HRQOL in neurological conditions (Cella, Lai, Nowinski, Victorson, Peterman, Miller, Bethoux, Heinemann, Rubin, & Cavazos, 2012; Cella, Nowinski, Peterman, Victorson, Miller, Lai et al., 2011). Included within this system are two measures of social functioning: Neuro-QoL Participation in Social Roles and Activities and Neuro-QoL Satisfaction with Social Roles and Activities. While there are data to support the validity of the scores on these measures in Parkinson's disease (Nowinski, Siderowf, Simuni, Wortman, Moy, & Cella, 2016), stroke (Sangha, Caprio, Askew, Corado, Bernstein, Curran et al., 2015), multiple sclerosis (Miller, Bethoux, Victorson, Nowinski, Buono, Lai et al., 2016), and adult epilepsy (Victorson, Cavazos, Holmes, Reder, Wojna, Nowinski et al., 2014), validity data have not yet been examined in HD.

This report provides data that support the reliability of the Neuro-QoL social functioning scores, as well as data that support the validity of test score interpretations in a large cohort of people with prodromal and clinically diagnosed HD (Carlozzi, Schilling, Lai, Paulsen,

Hahn, Perlmutter et al., 2016). Specifically, we examined internal consistency, floor and ceiling effects, convergent and discriminant validity, and known-groups validity of the scores on the Neuro-QoL social function measures.

Method

Participants

We examined individuals with prodromal HD (a positive test for the HD CAG gene mutation ≥ 36, without an HD clinical diagnosis) and those with a clinical diagnosis of HD. For people with HD, the Total Functional Capacity (Shoulson & Fahn, 1979), as determined by clinician-rated dministration, classified participants as either early stage (sum scores of 7 to 13) or later-stage HD (sum scores of 0 to 6, described below). Participants were at least 18 years of age, were able to read and understand English, and had the ability to provide informed consent. Participants were recruited through eight established HD Clinics, HD specialized nursing home units and support groups, the National Research Roster for Huntington's Disease, online medical record data capture systems (Hanauer, Mei, Law, Khanna, & Zheng, 2015), and articles/advertisements in HD-specific newsletters and websites. Participants were also recruited in conjunction with Predict-HD, a longitudinal observational research study in HD (Paulsen, Hayden, Stout, Langbehn, Aylward, Ross et al., 2006; Paulsen, Langbehn, Stout, Aylward, Ross, Nance et al., 2008; Paulsen, Long, Johnson, Aylward, Ross, Williams et al., 2014). All research was conducted in accordance with local institutional review boards; participants provided informed consent prior to their participation in this study and received $40 compensation for their participation.

PRO Measures

Neuro-QoL Social Functioning Measures—The Ability to Participate in Social Roles and Activities item bank (45 items) and the Satisfaction with Social Roles and Activities item bank (45 items) from the Neuro-QoL measurement system (Cella et al., 2011) were used in this study. Ability to Participate in Social Roles and Activities provided a measure of self-reported involvement in one's usual social roles and activities, whereas Satisfaction with Social Roles and Activities provided self-reported satisfaction with these same roles and activities. The computer-based static Short Form (Cella, Lai, Nowinski, Victorson, Peterman, Miller, Bethoux, Heinemann, Rubin, & Cavazos, 2012) versions of these measures (comprised of 8 items each), as well as the computer adaptive test (CAT) versions (Cella et al., 2011); assessments were administered through www.assessmentcenter.net. CAT administration is a test format where each item that is selected for administration is based on the participant's response to the previous item. Participants completed a minimum of 4 items in each CAT, and test administration stopped after either a standard error (SE) ≤ 0.3 was achieved or the participant answered 12 items. Item response theory based scores for all four of the measures were standardized using a ⊤ metric ($M = 50$, $SD = 10$); higher scores indicate better self-reported social health.

Generic PRO HRQOL Comparison Measures—Three generic measures of HRQOL were administered to compare psychometric properties with the Neuro-QoL scales. The WHODAS 2.0 (Ustun, Chatterji, Kostanjsek, Rehm, Kennedy, Epping-Jordan et al., 2010) is

a generic self-report measure of HRQOL that includes 12 items examining six subdomains of HRQOL: understanding and communication, self-care, mobility, interpersonal relations, work and household roles, and community and civic roles. Total scores range from 0 (highest level of health) to 48 (low health). The RAND-12 (Hays, Sherbourn, & Mazel, 1995) is also a generic self-report measure of HRQOL; it includes 12 items that examine physical and mental health. The RAND-12 can be used to generate two composite scores: Physical Health (PHC) and Mental Health (MHC). Both composite scores range from 0 (low health) to 100 (highest level of health). The EQ5D (Rabin & de Charro, 2001) is a 6-item self-report measure of generic health status. This measure can be used to generate a Health Scale score (which ranges from 0 [low health] to 100 [highest level of health]) and an Index Value score (which ranges from 0 [low health] to 1 [highest level of health]).

Self-Reported Social Functioning Composite Score—The generic HRQOL measures described above provide an appropriate general comparator for the Neuro-QoL Social Functioning measures, however, compared to the Neuro-Qol, they are broad by design (i.e., they are multi-dimensional). These generic measures are designed to assess physical, mental, and social well-being. The Neuro-QoL measures, in contrast, has several measures, each designed to assess only a single aspect of functioning (i.e., unidimensional), in this case social participation or social ability. Thus, to create a more “pure” generic comparator measure of social function (i.e., a measure that reflected more similar content), we selected items from the generic HRQOL measures to create a composite measure of self-reported social functioning. Items were selected that included face-valid content about social activities and interpersonal relationships. Selected items included 3 items (pertaining to the last 30 days) from the WHODAS (How much of a problem did you have joining in community activities?; How much difficulty did you have in dealing with people you do not know?; and How much difficulty did you have in maintaining a friendship?) and one item from the RAND-12 (During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities [like visiting friends, relatives, etc.]?). In order to create the composite score, the raw scores for each of the four items (scores were reversed where appropriate so that higher scores indicate better functioning) were transformed to *z*-scores (this was a linear transformation calculated using the sample SD for each item; resulting z-scores had a M = 0 and the SD = 1). These four *z*-scores were then averaged and transformed to a ⊤ score metric ($M = 50$, $SD = 10$); higher scores indicated better functioning.

Clinician-Rated Assessments of Functioning

The Unified Huntington's Disease Rating Scales (UHDRS; Huntington Study Group, 1996)—The UHDRS is a standardized clinical rating scale that assesses motor, cognitive, behavioral, and functional abilities. We examined four of these measures: Total Functional Capacity (TFC), Total Motor Score (TMS), Independence Scale, and Functional Assessment. The TFC is a 5-item measure that provides an index of day-to-day functioning across the domains of occupation, finances, domestic chores, activities of daily living, and care level; scores range from 0 to 13 (higher scores indicate better functioning). This measure is the most common method for staging HD. The TMS provides ratings of oculomotor function, dysarthria, chorea, dystonia, gait, and postural stability; higher scores

indicate greater motor dysfunction. The Independence Scale is rated from 0 to 100; higher scores reflect better functioning/greater independence. The Functional Assessment Scale includes a yes/no checklist of 25 common daily tasks related to occupation, finances, activities of daily living, domestic chores, level of care and physical abilities; scores range from 0 to 25 (higher scores indicate better functioning).

The Problem Behaviors Assessment Scale (PBA-s; Craufurd, Thompson, & Snowden, 2001)—The PBA-s is a clinician administered assessment of behavior. For the purposes of this study, we examined clinician-rated severity for Apathy. The Apathy Severity score was reversed and recoded as follows (8 = 0, 4 = 1, 3 = 2, 2 = 3, 1 = 4, 0 = 5); higher scores indicate less apathy.

Clinician-Rated Composite Score of Social Functioning—As with the self-report generic measures of HRQOL, we wanted to create a more "pure" clinician-rated comparator measure of social function (i.e., a measure that reflected more similar content), and thus, social functioning items from the clinician-rated assessments were used to create a clinician-rated composite score of social function. This clinician-rated composite included the UHDRS Independence Scale and the Apathy Severity score from the PBAs. In order to create the composite score, individual item scores were reversed (where appropriate) and transformed to z-scores (this was a linear transformation calculated using the sample SD for each item; resulting z-scores had M = 0 and SD = 1). These two z scores were then averaged, and transformed to a ⊤ score ($M = 50$, $SD = 10$); higher scores indicated better functioning.

Statistical analysis plan

Internal Consistency Reliability—Cronbach's alphas were calculated for the Neuro-QOL social function static form scores (minimal acceptable reliability was specified as ≥ 0.70; Cohen, 1988; DeVellis, 2017).

Floor and Ceiling Effects—Floor and ceiling effects were calculated as the proportion of participants with the lowest or the highest possible scores for the scores on the Neuro-QOL measures (minimal acceptable rates ≤ 20%; Andresen, 2000; Cramer & Howitt, 2004).

Timing Data—Median and SD timing data were examined for both CAT and Short Form versions of the Neuro-QoL measures.

Convergent and Discriminant Validity—A multi-trait multi-method correlation matrix was used to examine interrelationships among the NeuroQoL scores, the clinician-rated composite score, and the self-report composite score. Reliability coefficients were calculated to estimate the reliability of each measure in the matrix (minimal acceptable reliability ≥ 0.70; Cohen, 1988; DeVellis, 2017). Correlations between scores from measures of the same trait should be strongly correlated (i.e., social participation measures with one another); this provides evidence that supports convergent validity for test score interpretation. Correlations between scores of differing traits (i.e., social participation vs. general HRQOL) were examined for interpretation of discriminant validity. In addition, correlations between scores

from different methods (self-report with clinician report) should be less strongly correlated due both to method variance and because cognitive problems and anosognosia are common in HD; this also provides evidence for test score interpretation of discriminant validity. Correlations < 0.3 were considered poor, 0.3 to 0.6 adequate, and ≥ 0.6 good/very good evidence for test score interpretation of convergent validity (Campbell & Fiske, 1959).

Known-Groups Analyses—Analysis of variance (ANOVA) methods were used to examine group differences (i.e., prodromal, early- or late-HD) on the Neuro-QoL scores. We hypothesized that prodromal participants would report better functioning than both manifest HD groups, and that early-HD participants would report better functioning that late-HD participants.

Impairment Rates—We examined clinical impairment rates (participants whose scores were > 1 SD worse than the Neuro-QoL normative sample mean [n = 549; M = 50, SD = 10]; Cella, Lai, Nowinski, Victorson, Peterman, Miller, Bethoux, Heinemann, Rubin, Cavazos et al., 2012; Gershon, Lai, Bode, Choi, Moy, Bleck et al., 2012) to determine if individuals with HD were at greater risk than the general population for social impairments. According to the normal curve, 16% of the scores are expected to fall 1 SD below the mean (i.e., impaired); therefore, impairment rates that exceeded 16% indicate greater impairment than would be expected compared to demographically-comparable neurologically healthy peers (Heaton, Miller, Taylor, & Grant, 2004).

Effect sizes—Cohen's d was calculated to evaluate the relative influence overall functional severity had on Neuro-QOL social functioning scores (as determined by a median split using the matched “gold standard measure” – the UHDRS Independence Scale). Effect size calculations were computed for each measure based on comparison of each group relative to the means and standard deviations from the Neuro-QoL normative sample (again, n = 549; M = 50, SD = 10; Cella, Lai, Nowinski, Victorson, Peterman, Miller, Bethoux, Heinemann, Rubin, Cavazos, et al., 2012; Gershon et al., 2012). Effect sizes should be larger for the groups with more clinician-rated social functioning impairments.

Demographic Effects—We examined the relationships among age, gender, education and social function using Pearson correlations (for continuous variables) and point biserial correlations (for categorical variables).

Results

We enrolled 510 individuals with prodromal (n = 198) or manifest HD (n = 195 early HD and n = 117 late HD; Table 1). Groups did not differ on gender, χ^2 (2, N 510) = 3.53, p = . 17. There were small differences for education, F (2, 507) = 15.76, p < 0.0001; the early-HD and late-HD groups had 1 to 1.5 fewer years of education than the prodromal HD group. Groups differed on age, F (2, 507) = 46.47, p < .0001; the prodromal group (M = 42.74, SD = 12.02), was significantly younger than both manifest groups, and the early-HD group (M = 51.98, SD = 12.38) was significantly younger than the late-HD group (M = 55.07, SD = 11.89). Since disease progresses with age, this difference was anticipated.

Internal Consistency Reliability

Cronbach's alphas exceeded the minimum standard we established for minimal acceptable reliability for scores on both Neuro-QoL Social Functioning measures and was generally equal to or greater than scores for the general HRQOL scales (Table 2).

Floor and Ceiling Effects

Floor and ceiling effects were within acceptable limits for scores on all Neuro-QoL measures except for the Neuro-QoL Ability to Participate in Social Roles and Activities Short Form.

Timing Data

Median administration times for the Neuro-QoL measures were less than one minute (regardless of administration format; Table 3). On average CAT administration utilized fewer than 6 items (Ability to Participate in Social Roles and Activities M = 5.45 items, SD = 2.84; Satisfaction with Social Roles and Activities M = 5.74 items, SD = 3.21).

Convergent Validity

Reliability coefficients (in italics) for the Neuro-QoL Short Forms were good to excellent (. 88 for Satisfaction and .94 for Ability); the reliability coefficient for the self-report composite score was good (r = .81), whereas the reliability coefficient for the clinician rated composite score was sub-optimal (r = .46; Table 3). Validity coefficients (in bold) were adequate between the scores on the Neuro-QoL measures and the scores on the composite self-report measure, and good between the scores on the NeuroQoL measures and the scores on the clinician–rated composites.

Known-Groups Analyses

There were significant group differences on scores on the Neuro-QoL Social Functioning measures among all three HD groups for both Neuro-QoL measures (Table 4); Pillai's Trace =.14 F(4, 960) = 17.55, p < .0001, partial η^2 = .07 for the CATs and Pillai's Trace = .17 F (4, 950) = 21.65, p < .0001, partial η^2 = .08 for the Short Forms. For the CATs, prodromal HD participants indicated better social functioning (i.e., greater ability to participate and more satisfaction with social roles and activities) than both manifest HD groups, and individuals with early stage HD reported better social functioning than the late stage HD group on both measures. For the Short Forms, prodromal HD participants indicated better social functioning (i.e., greater ability to participate and more satisfaction with social roles and activities) than both manifest HD groups and individuals with early stage HD reported better social functioning ability than the late stage HD group; there were no group differences between individuals with early and late-stage HD on the Satisfaction Short Form.

Impairment rates

Overall impairment rates for our HD participants was comparable to the general population (general population 16%; Neuro-QoL Ability to Participate in Social Roles and Activities impairment rates = 17.5% for the CAT and 16.0% for the Short Form and Neuro-QoL Satisfaction with Social Roles and Activities impairment rates = 14.9% for the CAT and

7.7% for the Short Form). Examination by HD group indicated that impairment rates were within normal limits or exceeded normal rates for the prodromal and early-HD groups, but were elevated in the late-HD group for all measures except the Satisfaction Short Form (Table 3).

Effect sizes

Effect sizes are included in Table 5. As expected, effect sizes were larger for individuals with poorer social functioning.

Demographic Effects

Correlations between scores on social functioning measures and demographic variables were not significant. Specifically, scores on the Neuro-QoL Ability to Participate CAT and Short Form had weak relationships with age (r = -.09 for both), gender (r = -.05 and r = -. 10 for Ability and Satisfaction, respectively) and education (r = .09 and r = .14, for Ability and Satisfaction, respectively). Neuro-QoL Satisfaction CAT and Short Form scores had similar weak correlations with age (CAT r = -.12 and Short Form r = -.10), gender (CAT r = -.07 and short form r = -.05) and education (CAT r = .07 and Short Form r = .08).

Discussion

Findings suggest strong support that the Neuro-QoL measures of social functioning provide an excellent candidate for rigorously developed PROs of social functioning for HD; data indicate that scores on the Neuro-QoL measures of social functioning are reliable and test interpretation supports their validity.

Specifically, internal consistency was excellent (>.88 for both CAT and Short Form scores on the Neuro-QoL measures), and was generally higher than or equivalent to other scores from generic measures of HRQOL. Furthermore, the scores on CAT administrations comfortably exceeded established criterion for floor and ceiling effects (≤ 20%). Together, these findings indicate that these scores provide reliable measures of social function in HD.

Test score interpretations also supported the convergent validity of the Neuro-QoL social functioning measures. Specifically, scores on the Neuro-QoL measures demonstrated moderate relationships with scores on other self-report measures of social function and good relationships with clinician-rated scores of social function. In addition, test score interpretation also supported discriminant validity; correlations were lower for scores across less similar measures (i.e., self-report with clinician report). These findings are especially important because they provide support for a multimodal assessment approach (that includes both PRO and clinician-rated assessments), as well as suggesting that these generic social functioning measures are appropriate for use in individuals with HD.

Furthermore, consistent with the literature, we generally found that individuals with prodromal HD reported better social functioning than either manifest HD group, and individuals with late-HD reported the least satisfaction and ability to participate in social roles and activities of the three groups (Helder, Kaptein, van Kempen, van Houwelingen, & Roos, 2001; Read et al., 2013). The one exception was that the Satisfaction Short Form score

was unable to differentiate between individuals with early-and late-stage HD, suggesting that the CAT administration may be better for evaluating social satisfaction than the Short Form administration of this measure. In addition, social functioning "impairment" rates for individuals with HD were similar to or better than rates in the general population, but elevated for individuals with late-HD, again supporting test interpretation of construct validity and confirming previous findings (Helder et al., 2001; Read et al., 2013). Scores on the Neuro-QoL measures were also not related to demographic variables, providing additional evidence for construct validity. Finally, effect sizes for scores from the Neuro-QoL measures were larger for participants with the most social functioning difficulties. Together, the interpretation of these findings strongly support the construct validity of scores from the Neuro-QoL social measures in HD.

We acknowledge some study limitations. First, although we included scores from other self-report and clinician-rated measures/composites of social function as comparators, the selected items were generally non-specific and heterogeneous. In addition, age and disease severity are usually confounded HD (as HD symptoms worsen over time), thus it is difficult to separate their relationships to other variables. Although this confound complicates interpretations, the absence of a relationship between scores on the Neuro-QoL measures and age somewhat mitigates these concerns. Furthermore, while findings may not be generalizable to those prodromal participants with a high school or less education (as education levels for our prodromal participants were higher than the manifest groups), this limitation is somewhat mitigated by the absence of a relationship between the Neuro-QoL scores and education. In addition, although the racial breakdown of our sample is similar to other HD samples (given that HD is a euro-ethnic disease; Pringsheim, Wiltshire, Day, Dykeman, Steeves, & Jette, 2012), these findings may not be generalizable to those individuals with HD that are not Caucasian. These limitations are consistent with previous research and do not mitigate the overall contribution of this study to the field.

The Neuro-QoL social function measures provide brief, reliable scores of the ability to participate in and gain satisfaction from social roles and activities in persons with prodromal and manifest HD. In addition, test score interpretations of these measures support their concurrent, discriminant, and known groups validity in these same individuals. Future studies will examine change over time to determine clinical utility for repeated assessments in clinical trials; such studies will include responsiveness to change over time and establish the minimally important difference for each of these HD groups. In addition, future work should also examine the relationship between these self-reported HRQOL scores and other respondents (e.g., spouses, caregivers, and non-HD comparisons). Ultimately, these PROs of social functioning can provide useful information about social functioning in HD across the full HD spectrum. These measures can add breadth to treatment outcome measure options in HD and can increase understanding of the social implications of living with HD.

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Public Significance Statement

This study is designed to provide support for the reliability and validity of the scores from the Neuro-QoL social functioning patient-reported outcomes measures in Huntington disease. Scales with good reliability and evidence of validity are needed for improving the ability to measure social outcomes in Huntington disease. Furthermore, this paper is designed to encourage the use patient reported outcome measures in clinical research and practice.

Table 1
Demographic Information for Huntington disease participants

Variable	Prodromal (*n* = 198)	Early (*n* = 195)	Late (*n* = 117)	All (*N* = 510)
Age (Years)				
M (SD)	42.74 (12.17)	51.98 (12.38)	55.07 (11.89)	49.10 (13.23)
Gender(%)				
Female	63.6	54.4	59.8	59.2
Male	36.4	45.6	40.2	40.8
Race (%)				
Caucasian	97.5	96.4	93.2	96.1
Other	2.0	3.6	6.8	3.7
Unknown	0.5	0.0	0.0	0.2
Ethnicity (%)				
Not Hispanic or Latino	92.4	92.8	97.4	93.7
Hispanic or Latino	1.5	4.1	0.9	2.4
Not Provided	6.1	3.1	1.7	3.9
Education (# of years)				
M (SD)	15.91 (2.94)	14.71 (2.78)	14.22 (2.62)	15.06 (2.89)
Marital Status (%)				
Married	67.2	52.8	61.5	60.4

Table 2

Descriptive Information and Reliability Data for Study Measures

Measures	*n*	Cronbach's α	% of the sample with floor effects (high functioning)	% of the sample with ceiling effects (low functioning)	*M* (*SD*)	Administration Time in seconds *Mdn* (*SD*)
Neuro-QoL						
Satisfaction with Social Roles and Activities CAT *	483	--	19.3	0.0	48.94 (8.49)	37.0(54.97)
Satisfaction with Social Roles and Activities SF *	482	0.88	15.8	0.4	48.16 (6.69)	54.0 (40.15)
Ability to Participate in Social Roles and Activities CAT *	485	--	11.5	0.0	48.01 (8.63)	46.5 (79.91)
Ability to Participate in Social Roles and Activities SF *	481	0.94	29.9	0.4	48.87 (8.69)	45.0 (37.83)
COMPARATOR MEASURES						
Generic Self-Report Measures						
EQ5D Index Score *°	508	0.73	22.8	0.2	0.81 (0.15)	-
EQ5D Health Scale *°	508	-	8.9	0.6	79.49 (16.70)	-
Rand 12 PHS *	510	0.84	0.0	0.0	52.68 (7.63)	45.0 (67.84)
Rand 12 MHS *	510	0.84	0.0	0.0	53.93 (9.76)	45.0 (67.84)
WHODAS	476	0.94	19.5	0.0	21.13 (9.96)	70.0 (59.88)
Clinician-Rated Measures						
UHDRS Motor	496	0.97	9.9	0.2	26.14 (23.56)	-
UHDRS Functional Assessment	338	0.95	22.8	0.3	19.03 (6.38)	-
UHDRS TFC	508	0.72	11.6	1.0	8.94 (3.30)	-
COMPOSITE MEASURES						
Social Composite - Self *	479	0.81	0.0	0.0	50.07 (7.98)	36.0 (22.83)
Social Composite - Clinician *	464	0.46	28.9	0.0	50.17 (7.98)	-

Note. SRA = Social Roles and Activities; CAT = Computer Adaptive Test; SF = Short Form; PHC = Physical health Composite; MHC = Mental Health Composite; UHDRS = Unified Huntington's Disease Rating Scales; TFC = Total Functional Capacity

* higher scores = better functioning

° the paper form of the EQ5D was used for administration and timing data was not recorded

Table 3

Multi-Trait Multi-Method Correlation Matrix

		Satisfaction with SRA CAT	**Ability to Participate with SRA CAT**	**Social Composite – Clinician**	**Social Composite – Self**
		r	***r***	***r***	***r***
Neuro-QoL	Satisfaction with SRA CAT	*0.92*°			
	Ability to Participate with SRA CAT	0.67	*0.95*°		
Composite	Social Composite - Clinician	**0.50**	**0.45**	*0.46*	
	Social Composite - Self	**0.64**	**0.58**	**0.51**	*0.81*
		Satisfaction with SRA SF	Ability to Participate with SRA SF	Social Composite – Clinician	Social Composite – Self
		r	*r*	*r*	*r*
Neuro-QoL	Satisfaction with SRA SF	*0.88*			
	Ability to Participate with SRA SF	0.71	*0.94*		
Composite	Social Composite – Clinician	**0.46**	**0.53**	*0.46*	
	Social Composite - Self	**0.65**	**0.68**	**0.51**	*0.81*

Note. SRA = Social Roles and Activities; CAT = computer adaptive test; SF = Short Form; provided correlations are attenuated; numbers in italics reflect reliability coefficients;

° = CAT scores for the HD sample were simulated, and thus reliability coefficients could not be calculated, the provided reliability coefficients are based on the Neuro-QoL calibration sample (Gershon et al., 2012); numbers in bold reflect validity coefficients; all $p < 0.01$ level (2-tailed)

Table 4

Known Groups Validity for Neuro-QoL Social Functioning Computer Adaptive Tests

	Prodroma HD (CAT and SF *n* = 195)		Impaired	Early HD (CAT *n* = 186 and *SF n* = 185)		Impaired	Late HD (CAT *n* = 102 and SF *n* = 98)		Impaired	Overall Impaired	*F*	*p*	*Partial* η^2
	Mean	**SD**	**%**	**Mean**	**SD**	**%**	**Mean**	**SD**	**%**	**%**			
Computer Adaptive Tests													
Ability to Participate with SRA[a,b,c]	51.27	8.03	7.2	47.33	8.11	16.0	43.30	8.03	39.8	17.5	34.07	<0.0001	0.12
Satisfaction with SRA[a,b,c]	51.67	8.13	5.6	48.49	7.95	11.8	44.52	8.16	38.2	14.9	26.72	<0.0001	0.10
Short Forms													
Ability to Participate with SRA[a,b,c]	52.25	7.95	5.7	48.50	8.27	16.0	42.94	7.63	36.7	16.0	44.38	<0.0001	0.16
Satisfaction with SRA[a,b]	50.28	6.51	3.1	47.42	6.17	7.0	45.55	6.79	18.0	7.7	19.78	<0.0001	0.08

Note. HD = Huntington disease; CAT = computer adaptive test; SF = Short Form; SRA = Social Roles and Activities; there were significant differences among all three groups for all measures.

[a]=prodromal and early,

[b]=prodromal and late,

[c]=early and late

Table 5
Cohen's d Effect Sizes for Neuro-QoL Social Functioning Computer Adaptive Tests

NeurQOL Measure	UHDRS Independence Scale	
	Low Functioning	High Functioning
Ability to Participate with SRA CAT	-0.61	0.04
Satisfaction with SRA CAT	-0.52	0.15
Ability to Participate with SRA SF	-0.52	0.15
Satisfaction with SRA SF	-0.57	0.01

Note. CATs = computer adaptive tests; UHDRS = Unified Huntington's Disease Rating Scales; SRA = Social Roles and Activities.