© International Journal of Clinical and Health Psychology

ISSN 1697-2600 2009, Vol. 9, Nº 1, pp.21-35



Mood and quality of life among people with progressive neurological illnesses¹

Marita P. McCabe² (Deakin University, Australia), Lucy Firth (University of Melbourne, Australia), and Elodie O'Connor (Deakin University, Australia)

(Received December 19, 2007 / Recibido 19 de diciembre 2007) (Accepted July 15, 2008 / Aceptado 15 de julio 2008)

ABSTRACT. The current *ex post facto* study was designed to examine the mood and quality of life (QOL) among 423 people with progressive neurological illness. In particular, it investigated the relationship between illness variables and the mood and QOL of 120 people with motor neurone disease (MND), 48 with Huntington's disease (HD), 143 with Parkinson's and 112 with multiple sclerosis (MS). The results demonstrated that people with HD compared to the other illness groups experienced the most severe illness symptoms, poorest mood and lowest QOL. Psychological symptoms were the strongest predictor of mood and QOL for all groups, but there were some differences for each of the illness groups. The results of this study highlight the importance of developing information and treatment programs that are illness specific, as well as incorporating general strategies, so that people with progressive neurological illnesses can better cope with the symptoms of these disorders.

KEY WORDS. Huntington's disease. Mood. Motor neurone disease. Multiple sclerosis. Quality of life. Parkinson's. *Ex post facto* study.

¹ The authors would like to thank the Motor Neurone Disease Association of Victoria, Western Australia, South Australia and New South Wales, Australian Huntington's Disease Association of Victoria, South Australia/Northern Territory, Queensland, New South Wales, and Western Australia, Multiple Sclerosis Australia and Parkinson's Victoria for their support in this research.

² Correspondence: School of Psychology. Deakin University, 221. Burwood Highway. Burwood, Victoria 3125 (Australia). E-mail: marita.mccabe@deakin.edu.au

RESUMEN. El presente estudio *ex post facto* fue diseñado para examinar el estado de ánimo y la calidad de vida (QQL) entre 423 personas con enfermedad neurológica progresiva. En particular, se ha investigado la relación entre las variables de la enfermedad y el estado de ánimo y calidad de vida de 120 personas con enfermedad de la neuronales motoras (MND), 48 con enfermedad de Huntington (HD), 143 con Parkinson y 112 con esclerosis múltiple (MS). Los resultados demostraron que las personas con HD comparadas con los grupos con otras enfermedades experimentaban los síntomas más severos de enfermedad, el estado de ánimo más pobre y la más baja calidad de vida. Los síntomas psicológicos fueron predictores más fuertes del estado de ánimo y calidad de vida para todos los grupos, aunque hubo algunas diferencias entre los grupos de enfermedades. Los resultados de este estudio subrayan la importancia de desarrollar programas de información y tratamientos específicos en cuanto a la enfermedad junto con la incorporación de estrategias generalas para que las personas con enfermedades neurológicas progresivas puedan hacer frente a los síntomas de estos trastornos.

PALABRAS CLAVE. Enfermedad de Huntington. Estado de ánimo. Enfermedad de neuronales motoras. Esclerosis múltiple. Calidad de vida. Parkinson. Estudio *ex post facto*.

People with progressive neurological illnesses experience deteriorating health as a result of their illness. In addition, health problems are associated with higher levels of depression and anxiety, as well as poorer levels of quality of life - QOL (*e.g.*, Aronson, 1997; Behari, Srivastave, and Pandey, 2005). The current study was designed to examine the types of symptoms experienced by people with four progressive neurological illnesses: motor neurone disease (MND), Huntington's disease (HD), Parkinson's and multiple sclerosis (MS). In addition, the study examined the predictive role of these different symptoms in determining the mood and QOL of people with each of these neurological illnesses. No previous study was located that has examined differences in symptoms, mood and QOL between these illness groups in a single study. Further, previous research has not systematically investigated the predictors of mood and QOL for each of these illness groups.

MND is the name given to a group of diseases in which substantial degeneration of the motor neurones occurs. This degeneration results in progressive muscular atrophy and weakness (Robinson and Hunter; 1998). Symptoms of MND include involuntary muscle contractions and muscle atrophy, weakness and twitching. The individual may have problems with speech, chewing, swallowing and breathing. In the later stages of the disease the affected individual will become totally paralysed (Tamparo and Lewis, 2005). MND is usually fatal within 3-10 years after symptom onset, with death most commonly resulting from respiratory failure or aspiration pneumonia (Tamparo and Lewis, 2005). The mean age of onset is 66.1 years for males and 68.6 years for females, and is slightly more common in men than women (Glaetzer, 1998).

HD is an inherited, autosomal-dominant neurological condition determined by a genetic mutation on chromosome 4, and children of a person with HD have a 50 percent chance of developing the disease (Cummings, 1995). The gene for HD is passed from

parent to child and affects men and women equally. Brain cells in the central nervous system of a person with HD start to die, leading to a range of cognitive, physical and emotional symptoms. Individuals may suffer from short-term memory loss, difficulties with concentration, planning and judgement, involuntary movements, slowing of movements, twitching, slurred speech, swallowing difficulties, mood swings, aggression and depression (Quarrell, 2004). The onset of HD symptoms commonly occur between the ages of 35 and 55 years. The symptoms of HD worsen over time with the disease ending in death, usually due to infection, approximately 15 to 20 years after the onset of symptoms (Quarrell, 2004).

In Parkinson's, the nerve cells that produce dopamine, die earlier than usual, leading to a deficiency in the availability of this neurotransmitter. This dopamine deficiency leads to symptoms of Parkinson's; tremor, over rigidity of the muscles, slowness and uncoordinated movements (Goldsmith, 2001). Parkinson's by itself does not directly lead to death, and life expectancy with good treatment, is not much changed from normal life expectancy (Oxtoby, Williams, and Iansek, 2002). The age of onset is between 50 to 75 years and is slightly more common in men than women (Oxtoby *et al.*, 2002).

In people with MS, the myelin that protects nerve cells is damaged, which then blocks the electrical impulses travelling up and down the nerve. As a result, the nerves are unable to carry their signals effectively, leading to the early symptoms of MS (Burnfield, 2004). Symptoms of MS include motor and sensory disturbances, impaired vision, muscle weakness, paralysis, incontinence, fatigue, balance problems and numbness (Tamparo and Lewis, 2005). Symptoms vary significantly from person to person. The course of the disease is also varied, as is the progression. However, generally speaking, people with MS have a life expectancy of 50 years after onset (Tamparo and Lewis, 2005). The disease is more common in women than in men (Burnfield, 2004).

Previous research has clearly demonstrated that people with these progressive neurological disorders experience high levels of negative mood (*e.g.*, Do Prado and Barbosa, 2005; Kubler, Winter, Ludolph, Hautzinger, and Birbaumer, 2005; McCabe, 2005; Menza and Dobkin, 2005; Patten, Jacobs, Petcu, Reimer, and Metz, 2002; Paulsen, Ready, Hamilton, Mega, and Cummings, 2001). However, it does not appear to be inevitable that respondents experience negative mood symptoms, with some studies suggesting that people with these disorders are not at increased risk of depression and other psychological disorders (*e.g.*, Finger, 1998; Rabkin *et al.*, 2005; Richard *et al.*, 2004).

Research has also suggested that people with these neurological illnesses experience lower levels of QOL. Some of these studies have used comparative groups. For example, a study by McCabe and McKern (2002) demonstrated lower QOL among people with MS compared to the general population, and Rudick, Miller, Clough, Gragg, and Farmer (1992) found that the QOL of people with MS was worse than for people with inflammatory bowel disease or rheumatoid arthritis. Other studies have demonstrated that there is impairment in QOL among respondents with these illnesses, but they did not use a comparative group in their study design, and they did not examine differences in QOL between the illness groups (*e.g.*, Behari *et al.*, 2005; Helder, Kaptein, van Kempen, van Houwelingen, and Roos, 2001; Nortvedt, Riise, Myhr, and Nyland, 1999).

A limited number of studies have attempted to examine factors associated with increased negative mood and decreased QOL among people with these progressive neurological illnesses. For example, a study conducted among people with HD (Zappacosta *et al.*, 1996) demonstrated that psychiatric disorders were not associated with either length of illness or level of cognitive impairment. The experience of an exacerbation was found to lead to a negative impact on mood among people with MS (McCabe, 2005).

Provinciali, Ceravolo, Bartolini, Logullo, and Danni (1999) found no association between objective measures of the severity of illness among people with MS and either depression or QOL. Most other research has found a strong negative association between health related variables and QOL. Gulick (1997) found that health was an important predictor of QOL among people with MS. Fatigue seems to be a major factor impacting on QOL among people with MS (Aronson, 1997; Hemmett, Holmes, Barnes, and Russell, 2004). Depression symptoms and disease symptoms were found to predict QOL among people with Parkinson's (Slawek, Derejko and Las, 2005). McCabe (2005) also found a strong association between depression and QOL among people with MS.

The above research demonstrates that there is likely to be a negative impact on both mood and QOL due to the symptoms experienced by people with progressive neurological illness. However, it is not clear if particular symptoms are more likely to predict negative mood state and lower QOL. It is also not clear if there are differences between the illness groups in the impact of these symptoms, or if there are differences in the mood and QOL of people from each of the illness groups.

The current *ex post facto* study (Montero and León, 2007) was designed to determine the nature of the differences in symptoms experienced by people with MND, HD, Parkinson's and MS. It then examined the extent to which the various symptoms of these illnesses predicted mood and QOL among these respondents. Due to the lack of research in this area, it was not possible to generate hypotheses to test in the analyses. However, given the hereditary component of HD, it would be expected that people with HD may experience poorer mood and QOL than the other illness groups.

Method

Participants

Participants were 423 patients from four illness groups; motor neurone disease (MND), Huntington's disease (HD), Parkinson's, and multiple sclerosis (MS). Of the 423 patients, 120 (28%) had MND, 48 (11%) had HD, 143 (34%) had Parkinson's and 112 (27%) had MS, and. (see Table 1 for demographics data for each of the illness groups).

Materials

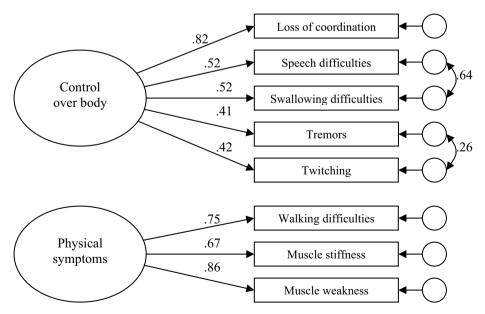
 Demographic measures. Participants were asked to provide background information on the variables listed in Table 1.

	Illness Group									
Characteristic	Motor neurone disease (n = 120)	Huntington's disease (n = 48)	Parkinson's $(n = 143)$	Multiple sclerosis (n = 112)	Total sample (n = 423)					
Age M (SD)	63.22 (12.43)	57.07 (10.87)	68.91 (8.15)	48.90 (11.81)	60.76 (13.35)					
Gender (% female)	40%	37%	50%	76%	53%					
Country of Birth (% Australian)	71%	82%	81%	89%	81%					
Education Level (% secondary or greater)	92%	89%	89%	98%	92%					
Marital Status (% married/de facto)	79%	83%	79%	63%	75%					
Age at Onset of Symptoms ($M \pm SD$)	57.28 ± 12.46	46.42 ± 9.35	59.72 ± 9.27	33.17 ± 11.59	$\begin{array}{c} 50.63 \pm \\ 15.61 \end{array}$					

TABLE 1. Patient characteristics by illness group.

Illness measures. Participants completed a symptoms scale which determined the severity of illness symptoms experienced. The scale consisted of 18 items, and participants were asked to rate their experience of symptoms such as «speech difficulties», «concentration difficulties», and «anxiety». The symptoms scale used in the current study was constructed from the description provided in the literature of the symptoms typical of patients with these disorders. Participants responded on a five-point Likert scale from 1 (not at all) to 5 (always). Factor analysis of this scale is described in the Results. See Figure 1 for the final 14 items included in this scale.

FIGURE 1. Structural equation model of illness symptoms.



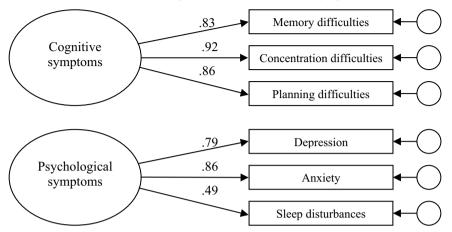


FIGURE 1. Structural equation model of illness symptoms (Cont.).

- Mood. Mood and psychological distress were measured using the short-form of the Profile of Mood States (POMS-SF; Curran, Andrykowski, and Studts, 1995). The current study used the items from the tension-anxiety, depression-dejection, fatigue-inertia, and confusion-bewilderment subscales as these were the scales that were expected to be most relevant for the participants in the current study. Participants responded on a five-point Likert scale from 0 (*not at all*) to 4 (*extremely*). In the present sample, internal reliability for all four subscales was high, Cronbach's $\alpha = .90$ to .94.
- Quality of Life. Participants rated their quality of life using the short-form of the World Health Organisation Quality of Life questionnaire (WHOQOL-BREF; WHOQOL Group, 1998). The 26-item scale measures four domains: *Physical health, Psychological health, Social relationships, and Environment*. It also includes an item measuring overall quality of life, and an item measuring satisfaction with health. Responses were on a five-point Likert scale from 1 (*very dissatisfied*) to 5 (*very satisfied*). The WHOQOL-BREF has been demonstrated to have good reliability and validity, and to correlate highly with the original WHOQOL-100 (WHOQOL-BREF; WHOQOL Group, 1998). In the present sample, Cronbach's α for each of the four domains ranged from .71 to .81.

Procedure

The Motor Neurone Disease Associations of Victoria, Western Australia, South Australia, and New South Wales, Australian Huntington's Disease Associations of Victoria, South Australia/Northern Territory, Queensland, New South Wales, and Western Australia, Parkinson's Victoria, and Multiple Sclerosis Australia, facilitated access to participants. Individuals with MND, HD, Parkinson's, and MS, were recruited by responding to a mail out or via notices published in each illness group's newsletter. Participants were provided with a statement outlining the study and gave their written consent to participate. Participants were then posted a questionnaire, with a reply-paid McCABE et al. Mood and quality of life in progressive neurological illnesses

envelope provided. While the exact rates of registration with the associations are unknown, it is estimated that between 85%-95% of people diagnosed with these illnesses are registered with their respective associations. Of the registered members who expressed interest in participating, either by returning a consent form, or by contacting the investigators, there was a 64% response rate for the return of completed questionnaires. This response rate was about the same for each of the illness groups. The actual number of participants is summarized in Table 1. The number of people with HD was lower than that for the other illness groups. The low number was primarily due to low number of people experiencing this disorder, and not to a lower response rate of participants in this group compared to the other illness groups.

The paper was edited according to the guide provided by Ramos-Álvarez, Moreno-Fernández, Valdés-Conroy, and Catena (2008).

Results

Confirmatory factor analysis of illness symptoms scale

The factor structure of the illness symptoms scale was examined using exploratory factor analysis via structural equation modelling (SEM) with AMOS 5.0. All latent variables were scaled by constraining the variances to one, and, due to chi-square being sensitive to a large sample size, model fit was instead assessed using a three-index strategy: SRMR (standardised root mean square residual); RMSEA (root mean-square residual); and CFI (comparative fit index), based on Byrne's (2001) recommendations. Good model fit was indicated by an SRMR value less than .80, a CFI value greater than .95, and an RMSEA value less than .08.

The original two-factor model (physical symptoms and psychological symptoms) produced a $\chi^2_{(132)} = 545.31$, p < .001 and CFI = .84, SRMR = .10, RMSEA = .09, indicating inadequate fit. Examination of the modification index values indicated that the physical symptoms item related to eye problems was highly related to the psychological symptoms factor, with a value of 31.71. This item was thus omitted from further analyses. Examination of the standardised parameter estimates indicated that memory, concentration, and planning, with loadings of .83, .92, and .85 respectively, loaded very strongly onto the psychological symptoms factor, while depression, anxiety, and sleep problems (with loadings of .48, .53, and .37 respectively) loaded less strongly. This indicated that these six items may be better specified as two separate factors. Memory, concentration, and planning appeared to represent cognitive symptoms, and depression, anxiety, and sleep problems represented psychological symptoms.

The next analysis tested this three-factor model (physical, cognitive, psychological), producing a $\chi^2_{(98)}$ = 293.52, *p* < .001 and CFI = .92, SRMR = .07, RMSEA = .07, indicating good fit. However, examination of the standardised residual covariances revealed that the pain and fatigue variables (physical symptoms items) were responsible for model mis-specification, with standardised residuals larger than 2.58. They also cross-loaded onto the cognitive and psychological factors. The incontinence item was also found to be responsible for model mis-specification. Thus, these three variables were omitted from further analyses. Examination of the modification indices indicated that there were

high error covariances between speech difficulties and swallowing difficulties (MI = 159.31), and between tremors and twitching (MI = 27.14). In addition, the standardised parameter estimates for the physical symptoms items were still fairly low, with a number of factor loadings falling around .30. The physical symptoms items seemed to be measuring two separate constructs; tremors, speech difficulties, swallowing difficulties, loss of coordination, and twitching appear to represent symptoms involved with control over the body, while walking difficulties, muscle stiffness, and muscle weakness appear to represent physical symptoms.

The final analysis tested this four-factor model, producing a $\chi^2_{(69)} = 143.35$, p < .001 and CFI = .97, SRMR = .05, RMSEA = .05, indicating excellent fit. Figure 1 details the standardised regression weights, and reveals that all items contributed strongly to the model.

Illness differences in mood, quality of life, and illness symptoms

Differences in mood, QOL, and illness symptoms between the four illness groups (MND, HD, Parkinson's and MS), were examined using a series of three MANOVAs. Means and standard deviations of the length of illness, illness symptoms, mood, and QOL, for each illness group is summarised in Table 2.

	Motor neurone disease	Huntington's disease	Parkinson's (n = 143)	Multiple sclerosi (n = 112)		
	(n = 120)	(n = 48)				
	M (SD)	M (SD)	M(SD)	M(SD)		
Length of illness (years)	5.67 (5.80)	12.13 (8.15)	9.19 (6.49)	15.77 (9.99)		
Symptoms						
Control over body	2.72 (.91)	3.01 (1.19)	2.36 (.69)	1.93 (.72)		
Physical	3.79(1)	2.87 (1.32)	3.11 (.93)	3.24 (1.13)		
Cognitive	1.77 (.89)	3.51 (1.13)	2.38 (.96)	2.49 (1.03)		
Psychological	2.43 (.95)	3.09 (1.13)	2.65 (.88)	2.48 (1.05)		
Mood						
Tension-Anxiety	7.19 (6)	9.86 (6.57)	7.20 (5.10)	5.60 (5.03)		
Depression-Dejection	11.15 (9.24)	11.97 (10.08)	6.45 (6.43)	6.96 (7.27)		
Fatigue-Inertia	11.31 (6.12)	9.70 (6.32)	8.77 (5.31)	11.09 (5.67)		
Confusion-Bewilderment	4.69 (4.94)	10.54 (5.91)	5.01 (4.28)	5.50 (4.76)		
Total mood score	8.21 (5.44)	10.43 (6.61)	6.65 (4.35)	7.21 (4.81)		
Quality of Life						
Physical	43.74 (19.78)	47.96 (20.53)	50.03 (18.58)	53.32 (17.53)		
Psychological	56.36 (19.52)	48.38 (22.98)	58.21 (14.30)	60.83 (17.92)		
Social relationship	62.65 (22.73)	49.13 (21.56)	61.93 (19.94)	62.42 (22.60)		
Environment	64.26 (16.95)	63.78 (18.92)	69.96 (14.25)	65.90 (16.84)		
Total quality of life score	56.80 (15.85)	52.17 (17.22)	60.15 (12.37)	60.92 (15.07)		

TABLE 2. Means and standard deviations of length of illness, mood, quality of life, and symptoms.

There was a statistically significant difference between illness groups on mood, $F_{(12, 1110)} = 15.05$, p < .001 partial eta squared = .14, with all four subscales reaching statistical significance: tension-anxiety, $F_{(3, 371)} = 6.14$, p < .001, partial eta squared=.05;

depression-dejection, $F_{(3,371)} = 9.62$, p < .001, partial eta squared = .07; fatigue-inertia, $F_{(3,371)} = 4.57$, p < .01, partial eta squared = .04; and confusion-bewilderment, $F_{(3,371)} = 21.61$, p < .001, partial eta squared = .15. Post-hoc comparisons using the Scheffe test are detailed in Table 3.

There was a statistically significant difference between illness groups on illness symptoms, $F_{(12, 1098)} = 21.59$, p < .001 partial eta squared=.19 with all four subscales reaching statistical significance: control over body symptoms, $F_{(3, 367)} = 45.16$, p < .001 partial eta squared = .15; physical symptoms, $F_{(3, 367)} = 41.62$, p < .001 partial eta squared = .09; cognitive symptoms, $F_{(3, 367)} = 88.40$, p < .001; partial eta squared = .20; and psychological symptoms, $F_{(3, 367)} = 12.71$, p < .001; partial eta squared = .04. Post-hoc tests using the Scheffe test were conducted, as it is the most conservative with respect to Type I error (Hair, Anderson, Tatham, and Black, 1998). Significant comparisons are detailed in Table 3.

TABLE 3. Level of significance of post-hoc Scheffe test comparisons.

Predictor	Motor ne with	Motor neurone disease with			Huntington's disease with			Parkinson with			Multiple sclerosis with		
	HD	Par	MS	MND	Par	MS	MND	HD	MS	MND	HD	Par	
Symptoms													
Control over body	.30	.04	.00	.30	.00	.00	.04	.00	.00	.00	.00	.00	
Physical	.00	.00	.01	.00	.32	.08	.00	.32	.80	.01	.09	.80	
Cognitive	.00	.00	.00	.00	.00	.00	.00	.00	.92	.00	.00	.92	
Psychological	.01	.45	.98	.01	.14	.02	.45	.14	.71	.98	.02	.71	
Mood													
Tension-Anxiety	.07	.99	.25	.06	.04	.00	.99	.04	.32	.25	.00	.32	
Depression-Dejection	.88	.00	.01	.88	.00	.01	.00	.00	.92	.01	.01	.92	
Fatigue-Inertia	.66	.02	1.0	.66	.73	.70	.02	.73.	.02	1.0	.70	.02	
Confusion- Bewilderment	.00	.73	.27	.00	.00	.00	.73	.00	.84	.27	.00	.84	
Quality of Life													
Physical	.66	.08	.00	.66	.92	.41	.08	.92	.59	.00	.41	.59	
Psychological	.07	.81	.19	.07	.01	.00	.81	.01	.64	.19	.00	.64	
Social Relationship	.01	.99	1.0	.01	.01	.01	.99	.01	.99	.1.0	.01	.99	
Environment	.99	.06	.87	.99	.12	.81	.06	.12	.34	.87	.81	.34	

Note. HD = Huntington's Disease, Par = Parkinson, MS = Multiple Sclerosis, MND = Motor Neurone Disease.

There was a statistically significant difference between illness groups on QOL, $F_{(12, 1191)} = 5.09$, p < .001, partial eta squared = .05. When the results for the dependent variables were considered separately, three of the four subscales reached statistical significance: physical QOL, $F_{(3, 398)} = 5.16$, p < .01; partial eta squared = .04; psychological QOL, $F_{(3, 398)} = 6.66$, p < .001, partial eta squared = .05; social relationship QOL, $F_{(3, 398)} = 5.21$, p < .01, partial eta squared = .04. However, environment QOL did not reach statistical significance, $F_{(3, 398)} = 3.31$, p = .02, partial eta squared = .02. Table 3 details post-hoc comparisons using the Scheffe test.

Predictors of mood: Illness symptoms and length of illness

Four standard multiple regressions were performed, with mood as the dependent variable, and length of illness, and the four illness symptoms subscales (control over body, physical, cognitive, and psychological) as independent variables, for each of the illness groups (see Table 4).

TABLE 4. Standardised regression coefficients for predictor variables in the multiple regression analysis examining the effect of symptoms and length of illness on mood.

	Motor neurone disease		Huntington's disease			Parkinson's			Multiple scl			
Predictor variable	β	р	sr^2	β	р	sr ²	β	р	sr^2	β	р	sr ²
Length of illness (years)	.07	.34		.05	.74		09	.26		04	.61	
Symptoms	16	0.5	0.2	0.0	0.2		0.2	70		0.2		
Control over body	.16	.05	.02	.06	.83		03	.78		.03	.77	
Physical	.07	.38		.07	.78		.28	.00	.04	05	.59	
Cognitive	.02	.82		.31	.12		.34	.00	.07	.40	.00	.09
Psychological	.66	.00	.29	.44	.01	.12	.34	.00	.07	.44	.00	.13

Note. $R^2 = .59$ for Motor Neurone Disease, .54 for Huntington's Disease, .55 for Parkinson's, .55 for Multiple Sclerosis.

For all four illness groups, the regressions were significantly different from zero. For MND participants, $F_{(5, 91)} = 25.89$, p < .001, with psychological symptoms and control over body symptoms making a significant contribution. For HD participants, $F_{(5, 29)} = 6.80$, p < .001, with psychological symptoms making a significant contribution. For Parkinson's participants, $F_{(5, 109)} = 26.59$, p < .001, with physical symptoms, cognitive symptoms, and psychological symptoms making a significant contribution. For MS participants, $F_{(5, 87)} = 21.34$, p < .001, with cognitive symptoms and psychological symptoms making a significant contribution. For MS participants, $F_{(5, 87)} = 21.34$, p < .001, with cognitive symptoms and psychological symptoms making a significant contribution to the prediction of mood. See Table 4 for a summary of the regression equations.

Predictors of quality of life: Illness symptoms, length of illness, and mood

A second series of four standard multiple regressions were performed, with QOL as the dependent variable, and length of illness, the four illness symptoms subscales (control over body, physical, cognitive, and psychological), and the four mood subscales (tension-anxiety, depression-dejection, fatigue-inertia, and confusion-bewilderment) as independent variables. Again, each illness group was examined separately (see Table 5).

Predictor variable	Motor	neurone	disease	Huntington's disease			Parkinson's			Multiple sclerosis		
	β	р	sr ²	β	р	sr ²	β	р	sr^2	β	р	sr^2
Length of illness (years)	.04	.63		21	.07		11	.17		.02	.80	
Symptoms												
Control Over Body	.03	.70		.26	.19		.05	.61		02	.89	
Physical	35	.00	.09	38	.05		34	.00	.05	15	.12	
Cognitive	23	.06		20	.24		.03	.78		05	.66	
Psychological	13	.30		43	.01	.08	05	.60		22	.04	.02
Mood												
Tension-Anxiety	47	.01	.04	.56	.02	.05	.01	.90		21	.13	
Depression-Dejection	24	.08		65	.01	.07	24	.02	.02	17	.22	
Fatigue-Inertia	.03	.81		.08	.60		08	.45		16	.10	
Confusion-Bewilderment	.33	.04	.02	23	.33		22	.09		04	.78	

TABLE 5. Standardised regression coefficients for predictor variables in the multiple regression analysis examining the effect of symptoms, length of illness, and mood on quality of life.

Note. $R^2 = .59$ for Motor Neurone Disease, .78 for Huntington's Disease, .54 for Parkinson's, .56 for Multiple Sclerosis.

All four regressions were significantly different from zero. For MND participants, $F_{(9, 87)} = 13.63, p < .001$, with the three physical symptoms, tension-anxiety, and confusion-bewilderment making a significant contribution. For HD participants, $F_{(9, 26)} = 10.51, p < .001$, with physical symptoms, psychological symptoms, tension-anxiety, and depression-dejection making a significant contribution. For Parkinson's participants, $F_{(9, 107)} = 14.20, p < .001$, with physical symptoms and depression-dejection making a significant contribution. For MS participants, $F_{(9, 83)} = 11.80, p < .001$, with psychological symptoms being the only variable to make a significant contribution. See Table 5 for a summary of the regression equations.

Discussion

The findings from the current study demonstrated that people with HD generally experienced the most severe deficits in the symptoms associated with their illness, their mood, and their QOL compared to the three other illness groups. In particular, people with HD experienced the least control over their bodily functions, the greatest difficulty with their cognitive functioning, and the greatest number of psychological symptoms. People with MND experienced the greatest number of physical symptoms. People with MS evidenced the best level of control over their body, and people with MND evidenced the best cognitive functioning.

Previous research has demonstrated that a number of the illness groups experience health related and psychological symptoms (*e.g.*, Do Prado and Barbosa, 2005; McCabe, 2005), but no previous studies have examined separate clusters of symptoms, or compared

the nature of the symptoms for each of the illness groups. The results demonstrate that the HD illness group reports the most severe symptoms in terms of movement, cognitive functioning and psychological functioning.

People with HD also reported higher levels of confusion than the other three illness groups; both MND and HD patients evidenced higher levels of anxiety and depression than the other two illness groups; and people with MND, HD, and MS evidenced higher levels of fatigue than those with Parkinson's. Thus the people who demonstrated the greatest problems in relations to mood were people with HD, followed by those with MND, MS and then those with Parkinson's. As for symptoms, no previous studies have directly compared the mood of people with different progressive neurological illnesses, although previous studies have certainly demonstrated that people with these illnesses experience a deterioration in their mood. It is difficult to ascertain why people with HD experience most problems in this area. Perhaps it is related to the more severe nature of the symptoms, or the fact that the illness has a strong genetic origin. Further research is necessary to determine reasons for these mood related differences between the groups, so that appropriate education and intervention programs can be developed.

An examination of the factors that predicted mood for people with HD demonstrated that the only significant predictor was psychological symptoms, even though people with this illness experienced high levels of other symptoms. Not surprisingly, psychological symptoms were significant predictors of mood for each of the illness groups, with a decline in cognitive functioning being an additional predictor for people with MS and Parkinson's, and an increase in physical symptoms also predicting mood among people with Parkinson's, and a lack of control over body functions predicting lower mood among people with MND. Clearly, symptoms are an important factor in predicting mood among people with these neurological illnesses, with between 54% and 59% of the variance in mood being explained by the length of time the respondents had experienced the illness, and the four sets of symptoms evaluated in this study. Developing educational programs to help people with these progressive neurological illnesses to cope with the symptoms of their illness may help them to better manage the symptoms, and so improve their mood. Further research is necessary to explore the success of such programs.

As for illness symptoms and mood, the QOL reported by people with HD generally demonstrated the greatest decrement compared to respondents with the other progressive neurological illnesses. These respondents experienced the greatest problems with their psychological QOL and social relationships. Other aspects of QOL did not evidence major differences between the illness groups. These results suggest that, consistent with previous research (*e.g.*, Behari *et al.*, 2005; McCabe and McKern, 2002), all the illness groups experience a decreased level of QOL, but that people with HD experience the greatest number of problems in this area.

In terms of the predictors of QOL, psychological and mood factors explained most of the variance for people with MND (anxiety, confusion), people with HD (physical symptoms, psychological symptoms, anxiety, depression), and people with MS (psychological symptoms). However, for people with Parkinson's, physical symptoms explained most of the variance in QOL, and this was also an important predictor of QOL among people with MND. The importance of these factors in predicting QOL among people with neurological illness is demonstrated by the finding that between 54% and 78% of the variance in QOL was explained by length of illness, symptoms and mood for people with these illness groups.

Future studies need to examine other factors that may predict mood and QOL among people with progressive neurological illnesses. Longitudinal studies need to be conducted to determine how symptoms, mood and QOL change over time, and the factors that predict these changes. The sample size for people with HD was very limited in the present study, primarily because of the lower prevalence of this illness compared to the other neurological illnesses. However, due to this small sample size, the results in relation to people with HD need to be treated with caution.

The results from this study have implications for intervention and educational programs for people with neurological disorders. Although they experience some common problems (particularly in relation to low mood), there are problems that are particular areas of concern for each of the illness groups. In particular, people with HD generally report more illness symptoms than the other groups of respondents, although people with MND experience more physical symptoms. Reasons for these differences and interventions to address the specific illness related needs of each of these population groups requires further research. As for illness symptoms, people with MND and HD were more likely to experience mood related problems than the other illness groups. Reasons for these differences need to be explored further. They may relate to the genetic origins of HD, and the generally rapid escalation on MND symptoms. However, this is only speculation, and needs to be confirmed with further research studies. Intervention programs to improve the QOL of people with these illnesses need to draw on the findings from the current study, and be designed to address the particular concerns of respondents from each of the illness groups.

References

- Aronson, K.J. (1997). Quality of life among persons with multiple sclerosis and their caregivers. *Neurology*, 48, 74-80.
- Behari, M., Srivastava, A.K., and Pandey R.M. (2005). Quality of life in patients with Parkinson's disease. Parkinsonism and Related Disorders, 11, 221-226.
- Burnfield, A. (2004). Need to know multiple sclerosis. Oxford: Harcourt Education.
- Byrne, B.M. (2001). Structural equation modeling with AMOS: Basic concepts, applications, and programming. Mahwah, New Jersey: Lawrence Erlbaum Associates.
- Cummings, J.L. (1995). Behavioural and psychiatric symptoms associated with Huntington's disease. *Advanced Neurology*, 65, 179-186.
- Curran, S.L., Andrykowski, M.A., and Studts, J.L. (1995). Short form of the profile of mood states (POMS-SF): Psychometric information. *Psychological Assessment*, 7, 80-83.
- Do Prado, R.C.P. and Barbosa, E.R. (2005). Depression in Parkinson's disease: Study of 60 cases. Arquivos de Neuro-Psiquiatria, 63, 766-771.
- Finger, S. (1998). A happy state of mind: A history of mild elation, denial of disability, optimism, and laughing in multiple sclerosis. *Archives of Neurology*, 55, 241-250.

- Glaetzer, K. (1998). Motor Neurone Disease: A Leaving Package for Professionals (1st ed.). *Palliative Profile*, 6, 5.
- Goldsmith, C. (2001). Neurological disorders. The amazing brain. Woodbridge, CT, USA: Blackbirch Press, Inc.
- Gulick, E. (1997). Correlates of Quality of life among persons with multiple sclerosis. *Nursing Research*, 46, 305-311.
- Hair, J.F., Anderson, R.E., Tatham, R.L., and Black, W.C. (1998). *Multivariate data analysis* (5th ed.). New York: Macmillan.
- Helder, D.I., Kaptein, A.A., van Kempen, G.M., van Houwelingen, J.C., and Roos, R.A. (2001). Impact of Huntington's disease on quality of life. *Movement Disorder*, 16, 325-330.
- Hemmett, L., Holmes, J., Barnes, M., and Russell, N. (2004). What drives quality of life in multiple sclerosis? QJM: An International Journal of Medicine, 97, 671-676.
- Kubler, A., Winter, S., Ludolph, A.C., Hautzinger, M., and Birbaumer, N. (2005). Severity of depressive symptoms and quality of life in patients with amytrophic lateral sclerosis. *Neurorehabilitation and Neural Repair*, 19, 182-193.
- McCabe, M.P. (2005). Mood and self-esteem of persons with multiple sclerosis following an exacerbation. *Journal of Psychosomatic Research*, 59, 161-166.
- McCabe, M.P. and McKern, S. (2002). Quality of life and multiple sclerosis: Comparison between people with multiple sclerosis and people from the general population. *Journal* of Clinical Psychology in Medical Settings, 9, 287-295.
- Menza, M. and Dobkin, R.D. (2005). Anxiety and Parkinson's Disease. *Primary Psychiatry*, 12, 63-68.
- Montero, I. and León, O.G. (2007). A guide for naming research studies in Psychology. International Journal of Clinical and Health Psychology, 7, 847-862.
- Nortvedt, M.W., Riise, T., Myhr, K.M, and Nyland, H.I. (1999). Quality of life in multiple sclerosis. *Neurology*, 53, 1098-1103.
- Oxtoby, M., Williams, A., and Iansek, R. (2002). Parkinson's at your Fingertips (2nd ed.). Adelaide: Flinders University.
- Patten, S.B., Jacobs, P., Petcu, R., Reimer, M.A., and Metz, L.M. (2002). Major depressive disorder and health care costs in multiples sclerosis. *International Journal of Psychiatry* in Medicine, 32, 167-178.
- Paulsen, J.S., Ready, R.E., Hamilton, J.M., Mega, M.S., and Cummings, J.L. (2001). Neuropsychiatric aspects of Huntington's disease. *Journal of Neurology, Neurosurgery,* and Psychiatry, 71, 310-314.
- Provinciali, L., Ceravolo, M.G., Bartolini, M., Logullo, F., and Danni, M.A. (1999). A multidimensional assessment of multiple sclerosis: Relationships between disability domains. *Acta Neurologica Scandinavica*, 100, 156-162.
- Quarrell, O. (2004). *Huntington's Disease: The facts*. New York, NY, USA: Oxford University Press.
- Rabkin, J.G., Albert, S.M., Del Bene, M.L., O'Sullivan, I., Tider, T., Rowland, L.P., and Mitsumoto, H. (2005). Prevalence of depressive disorders and change over time in latestage ALS. *Neurology*, 65, 62-67.
- Ramos-Álvarez, M.M., Moreno-Fernández, M.M., Valdés-Conory, B., and Catena, A. (2008). Criteria of the peer-review process for publication of experimental and quasi-experimental research in Psychology: A guide for creating research papers. *International Journal of Clinical and Health Psychology, 8*, 751-764.
- Richard, I.H., Frank, S., McDermott, M.P., Wang, H., Justus, A.W., Ladonna, K.A., and Kurlan, R. (2004). The ups and downs of Parkinson disease: A prospective study of mood and anxiety fluctuations. *Cognitive and Behavioral Neurology*, 17, 201-207.

Int J Clin Health Psychol, Vol. 9. Nº 1

- Robinson, I. and Hunter, M. (1998). *Motor Neurone Disease: The experience of illness series*. New York, NY, USA: Routledge.
- Rudick, R.A., Miller, D., Clough, J.D., Gragg, L.A., and Farmer, R.G. (1992). Quality of life in multiple sclerosis: Comparison with inflammatory bowel disease and rheumatoid arthritis. Archives of Neurology, 49, 1237-1242.
- Slawek, J., Derejko, M., and Lass, P. (2005). Factors affecting the quality of life of patients with idiopathic Parkinson's disease-a cross-sectional study in an outpatient clinic attendees. *Parkinsonism and Related Disorders*, 11, 465-468.
- Tamparo, C.D. and Lewis, M.A. (2005). *Diseases of the human body*. (4th ed.). Philadelphia: FA Davis Company.
- WHOQOL Group (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine*, 28, 551-558.
- Zappacosta, B., Monza, D., Meoni, C., Austoni, L., Soliveri, P., Gellera, C., Alverti, R., Mantero, M., Penati, G., Caraceni, T., and Girotti, F. (1996). Psychiatric symptoms do not correlate with cognitive decline, motor symptoms, or CAG repeat length in Huntington's disease. *Archives of Neurology*, 53, 493-497.