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A Comparison of Mood and Quality of Life Among People with Progressive Neurological Illnesses and Their Caregivers

Marita P. McCabe · Lucy Firth · Elodie O'Connor

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Abstract The current study was designed to investigate differences in mood and a range of QOL domains among 423 patients and 335 caregivers of people with motor neurone disease (MND), Huntington's disease (HD), Parkinson's, and multiple sclerosis (MS). Patients and caregivers completed an anonymous questionnaire that evaluated their mood (anxiety, depression, fatigue, confusion) and QOL (physical, psychological, social, environment). The results demonstrated that caregivers of people with MND and HD experienced most problems with their mood and QOL compared to caregivers of people in the other illness groups. There were few differences in mood or QOL between patients and caregivers. Patients generally showed greater confusion, physical impairment, and psychological maladjustment. The findings suggest that educational and intervention programs need to be developed to help both patients and their caregivers to adjust and cope with these illnesses, particularly caregivers of people with MND and HD.

Keywords Caregivers · Huntington's disease · Mood · Motor neurone disease · Multiple sclerosis · Parkinson's · Patients · Quality of life

Past research studies have demonstrated that people with progressive neurological illnesses experience high levels of negative mood (e.g., do Prado & Barbosa, 2005; Kubler, Winter, Ludolph, Hautzinger, & Birbaumer, 2005; McCabe, 2005; Menza & Dobkin, 2005; Patten, Jacobs, Petcu, Reimer, & Metz, 2002), and low quality of life (QOL) (e.g., Behari, Srivastava, & Pandey, 2005; Helder, Kaptein, van Kempen, van Houwelingen, & Roos, 2001; McCabe & McKern, 2002) as a result of their illness. However, there is also literature to suggest that the decline in mood and QOL is not inevitable, with some studies suggesting that QOL does not decline as the illness progresses (Rabkin, Wagner, & Del Bene, 2000; Simmonds, Bremer, Robbins, Walsh, & Fischer, 2000. There is less research on the impact of these illnesses on the mood and QOL among the caregivers of people with progressive neurological illnesses. The current study was designed to primarily focus on the level of negative mood and QOL of caregivers of people with progressive neurological illness. Mood and QOL of caregivers was compared to the mood and QOL of patients with these illnesses. The illness groups included in the current study were motor neurone disease (MND), Huntington's disease (HD), Parkinson's, and multiple sclerosis (MS). In addition, in order to obtain a measure of the differences in the burden of each of the illnesses, the mood and QOL of caregivers were compared between the illness groups. No previous study has performed this comparison across patients and caregivers of people with all of these illnesses, or between caregivers of people with these range of illnesses.

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 (Radunović, Mitsumoto, & Leigh, 2007; Robinson & 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

M. P. McCabe (✉) · E. O'Connor
School of Psychology, Deakin University, 221 Burwood Highway, Burwood, Melbourne, VIC 3125, Australia
e-mail: marita.mccabe@deakin.edu.au

L. Firth
University of Melbourne, Melbourne, Australia

(Tamparo & 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 & 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 (Cummings, 1995). The gene for HD is passed from parent to child and effects 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 occurs 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; Samii, Nutt, & Ransom, 2004). 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, & Iansek, 2002). The mean 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, cognitive impairment muscle weakness, paralysis, incontinence, fatigue, balance problems and numbness (Tamparo & 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 & Lewis, 2005). The disease is more common in women than in men (Burnfield, 2004).

Limited research has been conducted on the mood and QOL of caregivers of people with progressive neurological illnesses. Only three studies were located that evaluated the mood of these caregivers (Carter et al., 1998; Fernandez, Tabamo, David, & Friedman, 2001; Trail, Nelson, Van, Appel, & Lai, 2003). These studies found that caregivers of people with either MND or Parkinson's experienced high levels of depression, and this was related to the severity of illness of the patients. There have also been limited studies on the QOL of caregivers. Not surprisingly, this research has generally indicated a negative impact on the mood and QOL of caregivers. Pakenham, Bursnall, Chiu, Cannon, and Okochi (2006) found that caregivers of patients who experienced a range of physical or mental illness experienced lower life satisfaction than non-caregivers. Similar findings were obtained by O'Reilly, Finnan, Allwright, Smith, and Ben-Shlomo (1996). Kaub-Wittemer, Steinbűchel, Wasner, Laier-Groeneveld, and Borasio (2003) investigated the QOL of patients with amyotrophic lateral sclerosis (ALS—a form of MND) and their caregivers who had undergone a medical procedure to extend their life. The research demonstrated a high burden of care for caregivers. In fact, 30 percent of caregivers estimated their own QOL as lower than their patients' QOL. In contrast to this finding, Trail et al. (2003) found that although QOL was low in both patients and caregivers, the caregivers of patients with the same condition as the Kaub-Wittemer et al. (2003) study demonstrated no differences from patients in their levels of depression or QOL. Interestingly, patients overestimated caregivers' QOL, and caregivers underestimated patients' QOL. In a further study by Trail, Nelson, Van, Appel, and Lai (2004), the authors found that from an analysis of stressors on patients with ALS and caregivers of patients with ALS, patients were more stressed by their levels of dependency than caregivers, indicating a larger impact on the mood and QOL of patients with this condition compared to their caregivers.

Aubeeluck (2005) provided a general description of the low level of QOL of caregivers of people with HD. Helder et al. (2002) also found low levels of QOL among caregivers of people with HD, which were explained by the types of coping strategies they adopted. Kaptein et al. (2007) found that partners compared to patients with HD perceived that the patient experienced more symptoms, and that a belief that the patient would have a longer life expectancy was related to an improvement in the partner's QOL. No research was located that examined the QOL of caregivers of people with Parkinson's. Among caregivers of people with MS, Aronson (1997) found that poorer QOL was associated with the duration of caring, the severity of symptoms of the person with MS, and the disease course of the person with MS.

The above studies suggest that caregivers of people with progressive neurological illnesses are likely to experience negative mood and poorer QOL as a result of caring for the person with the illness. The current study was designed to determine differences between caregivers and patients in their mood and QOL. Further, it examined differences in

these two variables among caregivers in each of the four illness groups. The novel aspect of this study is that it provides a comparison of the mood and QOL of caregivers and patients using the same instruments. Further, it allows us to determine differences between the levels of adjustment of caregivers from each of the illness groups. The findings from this study have important clinical implications in terms of identifying the needs, and differences in the needs of patients and caregivers of people with a range of progressive neurological illnesses. Due to the paucity of research in this area, it was not possible to develop hypotheses regarding differences in mood and QOL between patients and caregivers, or to predict differences in the caregivers' mood or QOL between the illness groups. Although it would be expected that the psychological QOL domain would correlate highly with mood, separate measures of mood were obtained so that four different dimensions of mood could be evaluated.

Method

Participants

Participants were 423 patients and 335 caregivers 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. Fifty-three percent of patients were female, 81% were born in Australia, 92% had completed secondary school or greater, 75% were married or living in a de facto relationship, and the average age of the sample was 61 years of age (see Table 1). Of the 335 caregivers, 112 (33%) were caregivers for someone with MND, 73 (22%) were caregivers for someone with HD, 89 (27%) were caregivers for someone with Parkinson's and 61 (18%) were caregivers for someone with MS. Sixty-one percent of caregivers were female, 79% were born in Australia, 94% had completed secondary school or greater, 92% were married or living in a de facto relationship, and the mean age of the sample was 61 years of age (see Table 1). Most caregivers were spouses, but they were not generally related to the patient sample in this study.

Materials

Demographics

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

Mood

The short-form of the Profile of Mood States (POMS-SF; Curran, Andrykowski, & Studts, 1995) was utilised to measure mood and psychological distress. The widely used POMS was originally developed by McNair, Lorr, and Droppleman (1992), but was considered too long (65 items) for this population. For this reason, the POMS-SF was utilised, which is a 37-item short form demonstrated to have similar psychometric properties to the original POMS (Curran et al., 1995). The current study used the items from

Table 1 Patient and carer characteristics by illness group

	Patient illness group				
	MND	HD	Parkinson's	MS	Total sample
Patient characteristics	(n = 120)	(n = 48)	(n = 143)	(n = 112)	(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 (*SD*)	57.28 (12.46)	46.42 (9.35)	59.72 (9.27)	33.17 (11.59)	50.63 (15.61)
Carer characteristics	(n = 112)	(n = 73)	(n = 89)	(n = 61)	(n = 335)
Age M (*SD*)	60.51 (11.65)	59.58 (9.90)	67.31 (9.92)	55.02 (13.26)	61.10 (11.91)
Gender (% female)	68%	66%	63%	38%	61%
Country of birth (% Australian)	76%	77%	84%	75%	79%
Education level (% secondary or greater)	93%	96%	89%	98%	94%
Marital status (% married/de facto)	96%	80%	98%	89%	92%
Age at onset of symptoms M (*SD*)	57.75 (13.28)	44.97 (9.60)	58.72 (9.91)	35.94 (13.20)	51.30 (14.75)

the tension-anxiety, depression-dejection, fatigue-inertia, and confusion-bewilderment subscales. Participants were asked to rate how they had been feeling in the past week for items such as "tense", and "bewildered". 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 for both patients (Cronbach's $\alpha = .90$ to .94) and caregivers (Cronbach's $\alpha = .88$ to .96).

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 measured 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 Group, 1998). In the present sample, internal reliability (Cronbach's α) for each of the four domains ranged from .51 to .81 for patients and from .71 to .82 for caregivers.

Procedure

Approval to conduct the study was obtained from the University Human Ethics Committee. Multiple Sclerosis Australia, The Motor Neurone Disease Associations of Victoria, Western Australia, South Australia, and New South Wales, Parkinson's Victoria, and the Australian Huntington's Disease Associations of Victoria, South Australia/Northern Territory, Queensland, New South Wales, and Western Australia facilitated access to participants. Individuals with MS, MND, Parkinson's, and HD, and their caregivers, 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, which was to be completed within 6 weeks and posted back using the reply-paid envelope provided. While the exact rates of registration with the associations are unknown, it is estimated that between 85 and 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.

Results

Differences Between Patients on Mood and Quality of Life

Differences between MND, HD, Parkinson's, and MS patients have been examined in a separate paper (McCabe, Firth, & O'Connor, 2009). It was found that people with HD were generally more likely than the other groups to experience negative mood and lower QOL.

Differences Between Caregivers on Mood and Quality of Life

A MANOVA was conducted, in which the independent variable was illness type, while the dependent variables were the four mood subscales (tension-anxiety, depression-dejection, fatigue-inertia, and confusion-bewilderment). Due to violations of the assumption of equality of error variances, a more conservative alpha level of .01 was set for determining significance. There was a statistically significant difference between caregivers of people with the different illness groups on the combined dependent variables: $F(12, 867) = 3.66$, $p < .001$; $\eta^2 = .05$. Considered

Table 2 Means, standard deviations, and MANOVA results for differences between patients' and caregivers' mood

	Patients			Caregivers				
	N	*M*	*SD*	*N*	*M*	*SD*	*F*	*df*
Tension–anxiety								
MND	103	7.19	6.00	98	8.61	6.38	2.02	1, 199
HD	44	9.86	6.57	67	8.73	6.41	1.14	1, 109
PD	123	7.20	5.10	78	5.46	4.23	6.14	1, 199
MS	105	5.60	5.03	51	5.32	4.56	0.05	1, 154
Depression–dejection								
MND	103	11.15	9.24	98	10.09	8.91	0.28	1, 199
HD	44	11.97	10.08	67	10.95	8.65	0.32	1, 109
PD	123	6.45	6.43	78	5.35	6.55	0.86	1, 199
MS	105	6.96	7.27	51	4.40	5.15	4.52	1, 154
Fatigue–inertia								
MND	103	11.31	6.12	98	10.20	6.20	1.59	1, 199
HD	44	9.70	6.32	67	10.74	6.59	0.53	1, 109
PD	123	8.77	5.31	78	7.49	5.63	2.62	1, 199
MS	105	11.09	5.67	51	8.84	5.66	4.91	1, 154
Confusion–bewilderment								
MND	103	4.69	4.94	98	5.92	5.21	6.00	1, 199
HD	44	10.54	5.91	67	5.81	5.34	20.23***	1, 109
PD	123	5.01	4.28	78	3.47	3.63	8.55**	1, 199
MS	105	5.50	4.76	51	2.87	2.44	12.70***	1, 154

** $p < .01$; *** $p < .001$

Table 3 Means, standard deviations, and MANOVA results for patients' and caregivers' QOL

	Patients			Caregivers				
	N	*M*	*SD*	*N*	*M*	*SD*	*F*	*df*
Physical								
MND	114	43.74	19.78	93	66.44	17.80	78.90***	1, 218
HD	48	47.96	20.53	65	65.77	16.61	26.17***	1, 117
PD	130	50.03	18.58	77	66.36	16.92	41.64***	1, 213
MS	110	53.32	17.53	49	69.64	17.35	31.87***	1, 163
Psychological								
MND	114	56.36	19.52	93	61.32	18.59	3.74*	1, 218
HD	48	48.38	22.98	65	59.80	17.19	9.82**	1, 117
PD	130	58.21	14.30	77	66.71	11.63	21.62***	1, 213
MS	110	60.83	17.92	49	67.45	15.06	4.57*	1, 163
Social relationship								
MND	114	62.65	22.73	93	61.34	22.59	0.15	1, 218
HD	48	49.13	21.56	65	47.50	23.19	0.15	1, 117
PD	130	61.93	19.94	77	63.08	19.70	0.23	1, 213
MS	110	62.42	22.60	49	62.86	21.13	0.01	1, 163
Environment								
MND	114	64.26	16.95	93	66.70	16.94	0.86	1, 218
HD	48	63.78	18.92	65	64.01	17.14	0.05	1, 117
PD	130	69.96	14.25	77	71.62	13.88	0.37	1, 213
MS	110	65.90	16.84	49	68.37	15.53	0.49	1, 163

* $p < .05$; ** $p < .01$; *** $p < .001$

separately, all four subscales reached statistical significance: tension-anxiety, $F(3, 290) = 7.97$, $p < .001$; $\eta^2 = .08$; depression-dejection, $F(3, 290) = 11.87, p < .001; \eta^2 = .11$; fatigue-inertia, $F(3, 290) = 4.41$, $p < .01$; $\eta^2 = .04$; and confusion-bewilderment, $F(3, 290) = 9.13$, $p < .001$; $\eta^2 = .09$. Post-hoc comparisons using the Scheffe test are detailed in Table 4. As a general rule, caregivers of people with MND and HD demonstrated higher levels of anxiety depression, and confusion than the two other illness groups.

For the second MANOVA, the independent variable was illness type, while the dependent variables were the four QOL subscales (physical, psychological, social relationship, and environment). Again, an alpha level of .01 was set. There was a statistically significant difference between illness groups on the combined dependent variables: $F(12, 936) = 3.83$, $p < .001$; $\eta^2 = .05$. When the results for the dependent variables were considered separately, two of the four subscales reached statistical significance, psychological QOL, $F(3, 313) = 4.50$, $p < .01$; $\eta^2 = .04$; and social relationship QOL, $F(3, 313) = 8.50$, $p < .001$; $\eta^2 = .08$. However, physical QOL, $F(3, 313) = 0.73$, $p = .53$; $\eta^2 = .01$; and environment QOL, $F(3, 313) = 2.70$, $p = .05$; $\eta^2 = .03$ failed to reach statistical significance. Table 4 details post-hoc comparisons using the Scheffe test. In terms of social relationships, careers of people with HD and, in a lesser extent, MND showed the greatest decrements.

Differences Between Patients and Caregivers on Mood and Quality of Life

Differences in mood between patients and caregivers from each of the four illness groups were examined using a series of two-way MANOVAs. Means and standard deviations of mood and QOL for each illness group and each participant type are summarised in Tables 2 and 3 below.

A 2 (participant type; patient and carer) X 4 (illness group; MND, HD, Parkinson's, and MS) MANOVA was conducted on the four POMS subscales (tension-anxiety, depression-dejection, fatigue-inertia, and confusion-bewilderment). There was a significant difference in the mood of patients and caregivers: $F(4, 658) = 9.89$, $p < .001$; $\eta^2 = .06$. The multivariate interaction between participant type and illness group was also significant: $F(12, 1980) = 8.46$, $p < .001$; $\eta^2 = .05$. Multivariate analyses, using a Bonferroni adjusted alpha level of .013 to indicate statistical significance, demonstrated that only the confusion-bewilderment subscale was significantly different between patients and caregivers for the HD ($\eta^2 = .16$), Parkinson's ($\eta^2 = .04$), and MS ($\eta^2 = .08$) groups, with

Table 4 Significance levels of post-hoc Scheffe test comparisons for caregivers on mood and QOL

Predictor	MND with			HD with			Par with			MS with		
	HD	Par	MS	Par	MS	MND	MND	HD	MS	HD	Par	MND
Mood												
Tension–anxiety	1.0	.00	.01	.01	.02	1.0	.00	.01	1.0	.02	1.0	.01
Depression–dejection	.95	.00	.00	.00	.00	.95	.00	.00	.92	.00	.92	.00
Fatigue–inertia	.92	.04	.69	.92	.40	.01	.04	.01	.64	.40	.64	.69
Confusion–bewilderment	.99	.00	.00	.01	.01	.99	.00	.01	.98	.01	.98	.00
Quality of life												
Physical	1.0	1.0	.65	1.0	.63	1.0	1.0	1.0	.71	.63	.71	.65
Psychological	.96	.09	.14	.05	.08	.96	.09	.05	1.0	.08	1.0	.14
Social relationship	.00	.96	.98	.00	.00	.00	.96	.00	1.0	.00	1.0	.98
Environment	.85	.24	.95	.06	.63	.85	.24	.06	.71	.63	.71	.95

patients showing higher levels of confusion–bewilderment than their caregivers (see Table 2).

A second 2 (participant type; patient and carer) X 4 (illness group; MND, HD, Parkinson's and MS) MANOVA was conducted on the four WHOQOL subscales (physical, psychological, social relationships, and environment). There was a significant difference in the QOL of patients and caregivers: $F(4, 708) = 51.23$, $p < .001$; $\eta^2 = .22$. The multivariate interaction between participant type and illness group was also significant: $F(4, 710) = 4.04$, $p < .01$; $\eta^2 = .02$. Multivariate analyses were conducted using a Bonferroni adjusted alpha level of .013. Table 3 shows that, not surprisingly, for the physical subscale, patients showed significantly higher physical impairment than their caregivers for all four illness groups: MND ($\eta^2 = .27$); HD ($\eta^2 = .18$); Parkinson's ($\eta^2 = .16$); MS ($\eta^2 = .16$). There were no significant differences between patients and caregivers for any of the four illness groups on the social relationship or environment subscales. Patients showed significantly poorer psychological adjustment than caregivers for the HD ($\eta^2 = .08$) and Parkinson's ($\eta^2 = .09$) illness groups, but not for the MND or MS illness groups, although they also approached significance.

Discussion

The results of the current study demonstrate that caregivers of people with MND and HD experienced higher levels of anxiety, depression and confusion compared to caregivers of people with Parkinson's and MS. In terms of their QOL, there were no differences between the groups of caregivers on their physical QOL, but caregivers of people with HD experienced the greatest decrement in their social relationships compared to caregivers of people from the other illness groups.

Caregivers of people with MND and HD appear to require more support than the other illness groups. This may be due to the generally rapid escalation of symptoms among caregivers of people with MND (Tamparo & Lewis, 2005), and the need to adjust to the genetic origins of HD among caregivers of people with illness. Certainly, caregivers of people with HD have been shown to indicate that the patient experienced more symptoms of the illness than the patient (Kaptein et al., 2007), and this may place high levels of strain on these caregivers. Whatever the reason, it is important that targeted programs are developed to assist these particular groups of caregivers to cope with their role, in order to prevent them from developing psychiatric disorders due to the strain of the caring role. Respite care may also assist these caregivers to provide them with a break from the demands of providing care for patients with these illnesses. More research is required to determine the specific nature of the programs that would be most useful for caregivers of people from each of the illness groups in order to improve their mood and QOL.

An interesting finding from the current study was the difference between patients and caregivers on both mood and QOL. Not surprisingly, due to the nature of the illnesses (Goldsmith, 2001; Quarrell, 2004; Tamparo & Lewis, 2005), patients with HD, Parkinson's and MS demonstrated higher levels of confusion than caregivers. Patients from all illness groups also, not surprisingly, indicated higher levels of physical symptoms than caregivers. Further, patients, particularly those in the HD and Parkinson's groups, reported lower levels of psychological adjustment than caregivers.

A limitation of the current study was that the caregivers who participated in the study did not necessarily provide care for the patient participants. It is therefore not possible to draw conclusions regarding the mood and QOL of patients and their particular caregivers. Future research

needs to obtain information on mood and QOL of patients and their particular caregivers to allow this comparison to be made. Most caregivers in the current study were spouses, although some caregivers were parents or children. It was not possible in the current study to determine if the mood and QOL of spouses who were caregivers were different from parent and children who were caregivers. Future research is also needed to explore this issue further. Future research also needs to compare the current results with findings from the general population. McCabe and McKern (2002) found that QOL of people with MS was lower than for the general population and McCabe, McKern, and McDonald (2004) found that people with MS experience poorer psychological adjustment. However, comparison data have not been gathered for caregivers of these progressive neurological illnesses. Future research also needs to examine the role of length of time that the patient has experienced the illness, as well as severity of the illness, on mood and QOL of both patients and their caregivers.

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References

Aronson, K. J. (1997). Quality of life among persons with multiple sclerosis and their caregivers. *Neurology, 48*, 74–80.

Aubeeluck, A. (2005). Caring for the carers: Quality of life in Huntington's disease. *British Journal of Nursing, 14*, 452–454.

Behari, M., Srivastava, A. K., & Pandey, R. M. (2005). Quality of life in patients with Parkinson's disease. *Parkinsonism and Related Disorders, 11*, 221–226. doi:10.1016/j.parkreldis.2004.12.005.

Burnfield, A. (2004). *Need to know multiple sclerosis*. Oxford: Harcourt Education.

Carter, J. H., Stewart, B. J., Archbold, P. G., Inoue, I., Jaglin, J., Lannon, M., et al. (1998). Living with a person who has Parkinson's disease: The spouse's perspective by stage of disease. *Movement Disorders, 13*, 20–28. doi:10.1002/mds.870130108.

Cummings, J. L. (1995). Behavioral and psychiatric symptoms associated with Huntington's disease. *Advances in Neurology, 65*, 179–186.

Curran, S. L., Andrykowski, M. A., & Studts, J. L. (1995). Short form of the Profile of Mood States (POMS-SF): Psychometric information. *Psychological Assessment, 7*, 80–83. doi:10.1037/1040-3590.7.1.80.

do Prado, R. C. P., & Barbosa, E. R. (2005). Depression in Parkinson's disease: Study of 60 cases. *Arquivos de Neuro-Psiquiatria, 63*, 766–771.

Fernandez, H. H., Tabamo, R. E., David, R. R., & Friedman, J. H. (2001). Predictors of depressive symptoms among spouse caregivers in Parkinson's disease. *Movement Disorders, 16*, 1123–1125. doi:10.1002/mds.1196.

Glaetzer, K. (1998). Motor neurone disease: A learning package for professionals. (1st ed.). *Palliative Profile, 6*, 5.

Goldsmith, C. (2001). *Neurological disorders. The amazing brain*. Woodbridge, CT, USA: Blackbirch Press, Inc.

Helder, D. I., Kaptein, A. A., van Kempen, G. M., van Houwelingen, J. C., & Roos, R. A. (2001). Impact of Huntington's disease on quality of life. *Movement Disorders, 16*, 325–330. doi:10.1002/mds.1056.

Helder, D. I., Kaptein, A. A., van Kempen, G. M., Weinman, J., van Houwelingen, J. C., & Roos, R. A. (2002). Living with Huntington's disease: Illness perceptions, coping mechanisms, and spouses' quality of life. *International Journal of Behavioral Medicine, 9*, 37–52. doi:10.1207/S15327558IJBM0901_03.

Kaptein, A. A., Scharloo, M., Helder, D. L., Snoei, I., van Kempen, G. M., Weinman, J., et al. (2007). Quality of life in couples living with Huntington's disease: The role of patients' and partners' illness perceptions. *Quality of Life Research, 116*, 793–801. doi:10.1007/s11136-007-9194-4.

Kaub-Wittemer, D., Steinbűchel, N., Wasner, M., Laier-Groeneveld, G., & Borasio, G. D. (2003). Quality of life and psychosocial issues in ventilated patients with amyotrophic lateral sclerosis and their caregivers. *Journal of Pain and Symptom Management, 26*, 890–897. doi:10.1016/S0885-3924(03)00323-3.

Kubler, A., Winter, S., Ludolph, A. C., Hautzinger, M., & Birbaumer, N. (2005). Severity of depressive symptoms and quality of life in patients with amyotrophic lateral sclerosis. *Neurorehabilitation and Neural Repair, 19*, 182–193. doi:10.1177/1545968305276583.

McCabe, M. P. (2005). Mood and self-esteem of persons with multiple sclerosis following an exacerbation. *Journal of Psychosomatic Research, 59*, 161–166. doi:10.1016/j.jpsychores.2005.04.010.

McCabe, M. P., Firth, L., & O'Connor, E. (2009). Mood and quality of life among people with progressive neurological illness. *International Journal of Clinical and Health Psychology, 9*, 21–35.

McCabe, M. P., & 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. doi:10.1023/A:1020734901150.

McCabe, M. P., McKern, S., & McDonald, E. (2004). Coping and psychological adjustment among people with multiple sclerosis. *Journal of Psychosomatic Research, 56*, 35–361. doi:10.1016/S0022-3999(03)00042-4.

McNair, D. M., Lorr, M., & Droppleman, L. F. (1992). *Profile of Mood States manual*. San Diego, California: Educational and Industrial Testing Service.

Menza, M., & Dobkin, R. D. (2005). Anxiety and Parkinson's disease. *Primary Psychiatry, 12*, 63–68.

O'Reilly, F., Finnan, F., Allwright, S., Smith, G. D., & Ben-Shlomo, Y. (1996). The effects of caring for a spouse with Parkinson's disease on social, psychological and physical well-being. *British Journal of General Practice, 46*, 507–512.

Oxtoby, M., Williams, A., & Iansek, R. (2002). *Parkinson's at your fingertips* (2nd ed.). Adelaide: Flinders University.

Pakenham, K. I., Bursnall, S., Chiu, J., Cannon, T., & Okochi, M. (2006). The psychosocial impact of caregiving on young people who have a parent with an illness or disability: Comparisons between young caregivers and noncaregivers. *Rehabilitation Psychology, 51*, 113–126. doi:10.1037/0090-5550.51.2.113.

Patten, S. B., Jacobs, P., Petcu, R., Reimer, M. A., & Metz, L. M. (2002). Major depressive disorder and health care costs in multiples sclerosis. *International Journal of Psychiatry in Medicine, 32*, 167–178. doi:10.2190/K05D-XER3-WT4Y-FDQV.

Quarrell, O. (2004). *Huntington's disease: The facts*. New York, NY, USA: Oxford University Press.

Rabkin, J. G., Wagner, G. J., & Del Bene, M. (2000). Resilience and distress among amyotrophic lateral sclerosis patients and caregivers. *Psychosomatic Medicine, 62*, 271–279.

Radunović, A., Mitsumoto, H., & Leigh, P. (2007). Clinical care of patients with amyotrophic lateral sclerosis. *Lancet Neurology, 6*, 913–925. doi:10.1016/S1474-4422(07)70244-2.

Robinson, I., & Hunter, M. (1998). *Motor Neurone Disease: The experience of illness series*. New York, NY, USA: Routledge.

Samii, A., Nutt, J. G., & Ransom, B. R. (2004). Parkinson's disease. *Lancet, 363*, 1783–1793. doi:10.1016/S0140-6736(04)16305-8.

Simmonds, S., Bremer, B. A., Robbins, R. A., Walsh, S. M., & Fischer, S. (2000). Quality of life in ALS depends on factors other than strength and physical function. *Neurology, 55*, 388–392.

Tamparo, C. D., & Lewis, M. A. (2005). *Diseases of the human body* (4th ed.). Philadelphia: FA Davis Company.

Trail, M., Nelson, N. D., Van, J. N., Appel, S. H., & Lai, E. C. (2003). A study comparing patients with amyotrophic lateral sclerosis and their caregivers on measures of quality of life, depression, and their attitudes toward treatment options. *Journal of the Neurological Sciences, 209*, 79–86. doi:10.1016/S0022-510X(03)00003-0.

Trail, M., Nelson, N. D., Van, J. N., Appel, S. H., & Lai, E. C. (2004). Major stressors facing patients with amyotrophic lateral sclerosis (ALS): A survey to identify their concerns and to compare with those of their caregivers. *Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders, 1*, 40–45. doi:10.1080/14660820310016075.

WHOQOL Group. (1998). Development of the World Health Organization WHOQOL-BREF Quality of Life Assessment. *Psychological Medicine, 28*, 551–558. doi:10.1017/S0033291798006667.