

A longitudinal study of quality of life among people living with a progressive neurological illness

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ABSTRACT

This study investigated predictors of quality of life (QOL) of people with progressive neurological illnesses. Participants were 257 people with motor neurone disease (MND), Huntington's disease (HD), multiple sclerosis (MS), or Parkinson's. Participants completed questionnaires on two occasions, 12 months apart. There was an increase in severity of symptoms for people with MND, negative mood for people with HD and Parkinson's, and social support satisfaction for people with MS. Regression analyses were conducted to determine predictors of QOL for each group. Predictor variables were length of illness, symptoms (physical symptoms, control over body, cognitive symptoms and psychological symptoms), mood, relationship satisfaction and social support. Predictors of QOL were severity of symptoms for people with MND, HD and MS; negative mood for people with MND and Parkinson's; and social support satisfaction for people with MS. These results demonstrate the importance of illness severity and mood in predicting QOL, but also indicate differences between illness groups. The limited role played by social support and relationship is a surprising finding from the current study.

Keywords: Quality of Life; Neurological Illness; Mood; Social Support

1. INTRODUCTION

The current study evaluated factors predicting quality of life (QOL) of people with progressive neurological illnesses. The most common illness groups and so those included in the current study were people with motor

neurone disease (MND), Huntington's disease (HD), multiple sclerosis (MS), and Parkinson's. Symptoms associated with these disorders can be found in Tamparo and Lewis [1] for MND, Quarrel [2] for HD, Burnfield [3] for MS and Oxtoby, Williams, and Iansek [4] for Parkinson's. These are all illnesses that generally affect individuals from early to late mid-life, and research has demonstrated that many people who experience these illnesses have a diminished QOL [5-7]. What is not clear is what factors from a broad biopsychosocial theoretical perspective predict the QOL of people with these illnesses over time, and if there are differences in these predictors between the illness groups.

The specific factors that were examined in the current study were severity of illness, in combination with the psychosocial factors of mood, relationship satisfaction and levels of social support. These variables were selected to reflect the biopsychosocial theory of adjustment. This theory was originally developed by Engel [8] to explain the variables that contribute to health and illness. Sarafino [9] further developed this model, and suggested that it is the interplay between these biopsychosocial factors that explains the nature and causes of illness. Cooper, Stevenson, and Hale [10] also utilized this model, and found that each of the components of the model are complementary to one another, and that change in one variable is associated with variation in other variables.

Within this framework, it is proposed that one's adjustment and QOL are shaped by biological factors (these may be inherited characteristics, or current physical functioning), psychological factors that relate to the individual's current psychological state, and broader social or environmental factors that impinge on the individual. In the current study, the biological variable was the severity of illness, the psychological variable was mood, and the social variables were relationship satisfaction and social support.

Past research has demonstrated mixed results in the

association between severity of illness and QOL for people with these illnesses. For example, Gulick [11] and Hemmett, Holmes, Barnes, and Russell [12] both demonstrated that health and fatigue were major factors predicting QOL among people with MS. In contrast, Provinciali, Ceravolo, Bartolini, Logullo, and Danni [13] found no association between objective measures of severity of illness and QOL among respondents with MS. Likewise, Slawek, Derejko, and Lass [14] found a strong association between objective severity of illness and QOL among people with Parkinson's. In contrast, Reuther *et al.* [15] found an inverse relationship between QOL and severity of illness during the previous 12 months among people with Parkinson's. Clearly, further research is necessary on the association between disease severity and QOL; how both of these factors change over time, as well as the extent to which the severity of the disease predicts QOL over time, and how this differs for people from different illness groups. No studies were located that had examined the association between disease severity and QOL in MND or HD.

The second set of variables to be considered in this study were psychological factors, with negative mood being the variable that is most likely to be associated with QOL in the current group of participants. In a cross-sectional study of people with Parkinson's [14] and a longitudinal study of people with MS [16], depression was associated with a lower QOL. Beal, Stuijbergen, and Brown [17] also found that there was no major change in the high rates of depression among people with MS over a seven years period, although a greater length of time of experiencing MS, and greater number of illness related symptoms was associated with higher levels of depression at the commencement of the study. No studies were located that have examined the association between mood and QOL in the other illness groups.

In the theoretical framework utilized for the current study, there has been limited investigation of the social variables. In particular, the role of relationships and social support on the QOL of people with these progressive neurological illnesses has not been extensively studied. Phillips and Stuijbergen [18] conducted a cross-sectional study that found that among people with MS, the number of positive experiences was strongly associated with higher levels of QOL. Likewise, McCabe [19] found that social support was a predictor over time of various domains of QOL among people with MS. In a cross-sectional investigation, Winter *et al.* [20] emphasised the important role of social support in the QOL of people with Parkinson's. Given that social support and relationship satisfaction may be protective factors for the QOL of people with progressive neurological illnesses, it is important to conduct further research to explore these associations further.

The above literature indicates the important role that biopsychosocial factors appear to play in the QOL of people with neurological illnesses. The extent to which this biopsychosocial framework (disease symptoms, mood, relationship satisfaction, and social support) predicts QOL among people with progressive neurological illnesses (MND, HD, MS, Parkinson's) over a 12 months period (time 2) was evaluated in the current study. It was expected that high levels of negative mood at time 1 would predict lower levels of QOL at time 2, and high levels of relationship satisfaction and social support at time 1 would predict higher levels of QOL at time 2 among each of the illness groups. On the balance of the literature, it was predicted that high severity of illness at time 1 would predict lower QOL at time 2. From the limited literature that is available, it was not possible to predict how these relationships would vary for the different illness groups.

2. METHOD

2.1. Participants

Participants were 257 people living with a neurological illness; 52 (20%) males and females with motor neurone disease (MND), 26 (10%) males and females with Huntington's disease (HD), 79 (31%) males and females with multiple sclerosis (MS), and 100 (39%) males and females with Parkinson's. The age distribution was as follows: mean = 62.27, ($SD = 11.64$) for people with MND; mean = 59.15, ($SD = 9.64$) for people with HD; mean = 50.12, ($SD = 11.95$) for people with MS; and mean = 70.05, ($SD = 7.71$) for people with Parkinson's. The mean length of illness in years for each of the groups was 5.67 ($SD = 5.80$) for MND, 12.13 ($SD = 8.15$) for HD, 15.77 ($SD = 9.99$) for MS and 9.19 ($SD = 6.49$) for Parkinson's.

2.2. Materials

2.2.1. Quality of Life (QOL)

Participants rated their QOL using the short-form of the World Health Organisation Quality of Life questionnaire (WHOQOL-BREF) [21]. The 26-item scale measured four domains: physical health, psychological health, social relationships, and environmental mastery. It also includes an item measuring overall QOL, 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 [21]. The total score ranged from 0 to 100. Coefficient Alpha in the current study ranged from 0.47 for the physical subscale to 0.83 for the environment subscale. The total score was obtained by adding all of the sub-scales, and the Coeffi-

cient Alpha for this total score ranged from 0.85 to 0.89.

2.2.2. Mood

The short-form of the Profile of Mood States (POMS-SF) [22] was utilised to measure mood and psychological distress. The widely used POMS was originally developed by McNair, Lorr, and Droppleman [23], 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 [23]. The current study used the items from 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 on a five-point Likert scale from 0 = not at all to 4 = extremely for items such as “tense”, and “bewildered”. The total score varied from 0 to 24. Coefficient Alpha for each of the subscales in the current study ranged from 0.89 to 0.96.

2.2.3. Relationship Satisfaction

Participants completed the 7-item Relationship Assessment Scale (RAS) [24], which forms a one-factor generic measure of relationship satisfaction. Participants were asked to answer questions such as “How well does your partner meet your needs” on a five-point Likert scale from 1 = not at all to 5 = always. Total scores ranged from 1 to 5. The RAS has been demonstrated to have good test-retest reliability and to correlate highly with other measures of marital satisfaction [25]. Coefficient Alpha in the current study ranged from 0.85 to 0.88. Participants who were not involved in a relationship were asked to leave the items on this scale blank.

2.2.4. Social Support

Participants completed the Satisfaction with Social Supports subscale from the short-form of the Social Supports Questionnaire (SSQ) [26]. The SSQ contains six items and asks participants to rate their satisfaction with social supports for six different situations; for example, “How satisfied are you with the number of people you can count on to console you when you are very upset”. The items were rated on a six-point Likert scale from 1 = extremely dissatisfied to 6 = extremely satisfied. Total scores ranged from 1 to 6. The short-form of the SSQ has been found to correlate well with the original SSQ [27], and to have high internal reliability [26]. Coefficient Alpha in the current study ranged from 0.94 to 0.95.

2.2.5. Symptom Severity

Participants completed a symptoms scale which determined the severity of illness symptoms. The scale was developed for this study and consisted of 18 items. Participants were asked to rate their experience of symptoms

such as “speech difficulties”, “concentration difficulties”, and “anxiety”. The factor structure of the symptoms scale has been examined in a separate paper [28]. Based on these analyses, symptoms were divided into four subscales: physical symptoms, control over body, cognitive symptoms, and psychological symptoms. The physical, cognitive, and psychological symptoms subscales consisted of three items each, while the control over body symptoms subscale contained five items. Participants responded on a five-point Likert scale from 1 = not at all to 5 = always. Scores for each of the subscales and for the total scale score ranged from 1 to 5. In the present sample, Cronbach's α was ≥ 0.80 for physical symptoms, ≥ 0.74 for control over body, ≥ 0.90 for cognitive symptoms, and ≥ 0.73 for psychological symptoms.

2.3. Procedure

Ethics approval for the study was obtained from the University 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. 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. Participants were recruited by responding to 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 six weeks and posted back using the reply-paid envelope provided. Twelve months later, those who had participated in the baseline questionnaire were posted a follow-up questionnaire. From the 423 participants who completed the baseline questionnaire, a total of 257 (61%) completed the twelve-month follow-up. Reasons for non-response at follow up were difficult to determine, but given the nature of these illnesses it is likely that a proportion of the non-respondents (particularly those with MND and HD) would have passed away. There were no significant differences between the time 1 levels of the variables measured in the current study (each of the independent and dependent variables, age and length of illness for each of the illness groups) between responders and non-responders at time 2.

3. RESULTS

3.1. Changes over Time

A series of paired-samples *t*-tests were conducted to

evaluate changes in quality of life, mood, relationship satisfaction, social support, and symptoms over the twelve month period. Means and standard deviations are presented in **Table 1**.

The results revealed that, for people with MND, severity of symptoms significantly increased over the twelve-month period, $t(46) = -2.26, p < 0.05$. For people with both HD and Parkinson's, negative mood significantly increased over time, $t(21) = -2.27, p < 0.05$ and $t(78) = -2.31, p < 0.05$ respectively. For people with MS, social support satisfaction increased over the twelve month period, $t(74) = -2.23, p < 0.05$. There were no changes in QOL or relationship satisfaction for any of the groups over time.

3.2. Predictors of Quality of Life

A hierarchical multiple regression was conducted for each of the four illness groups, to determine whether mood, marital relationship satisfaction, social support satisfaction, and symptom severity at time One predicted QOL at time Two, after controlling for length of illness. The total of the WHOQOL-BREF was used as the dependent variable. Length of illness at time 1 was entered on Step 1 of the analysis, and time 1 levels of the other variables were entered on Step 2. **Table 2** displays the standardised regression coefficients (β), significance level (p), and semipartial correlations (sr^2) for each of these regressions. There was no evidence of multicollinearity between the independent variables, with any correlations being <0.60 for all groups.

For MND patients, the regression was significantly different from zero, $F(5, 33) = 9.50, p < 0.001, R^2 = 0.59$. Negative mood and severe symptoms were significant predictors of low QOL. For HD patients, the regression was significantly different from zero, $F(5, 9) = 6.63, p < 0.01, R^2 = 0.79$. Only severe symptoms significantly predicted low QOL. For MS patients, the regression was significantly different from zero, $F(5, 40) = 10.78, p < 0.001, R^2 = 0.57$. Severe symptoms and low social support satisfaction both significantly predicted low QOL. Finally, for Parkinson's patients, the regression was significantly different from zero, $F(5, 55) = 18.31, p < 0.001, R^2 = 0.63$. Significant predictors of low QOL were having the illness for a greater number of years, and high levels of negative mood.

4. DISCUSSION

Given the relatively rapid escalation of the illness, it was not surprising to find that the severity of symptoms showed a significant increase over a 12-month period for people with MND [1]. Further, given the changes in cognitive functioning that are associated with HD [2], it is possible that this particular change in symptom may con-

tribute to the increases in negative mood that occurred among these participants over time. There was also an increase in negative mood among people with Parkinson's, which may also be associated with the demands of coping with the symptoms of this illness [29]. There were no changes in negative mood for the other illness groups, which is consistent with past findings for people with MND [30]. Interestingly, there was an increase in satisfaction with social support among people with MS. It is possible that this group of respondents either experienced limited relapses in their illness, or called upon and received social support to cope with their illness related symptoms.

It is interesting to note that there were no changes in the QOL or relationship satisfaction of any of the illness groups over the 12-month period. This finding in relation to QOL is consistent with that of Gauthier *et al.* [30], who examined the QOL of people with MND over a nine month period. This level of stability suggests that people with these illnesses settle into a pattern of life once they have adjusted to their diagnosis and that, at least over this period of 12 months, their overall QOL remains quite stable. Perhaps this also explains the lack of change in relationship satisfaction. Respondents have settled into a way of relating to one another, and perhaps major changes in satisfaction with the relationship only occur in the early stages of the illness and over a longer period of time (respondents in the current study had already experienced the illness for more than 12 months).

Consistent with the nature of the symptoms experienced by people with these illnesses, high levels of symptomology predicted lower QOL over a 12-month period for people with MND, HD, and MS. These results are consistent with previous research that has demonstrated the important detrimental impact of illness related symptoms on the QOL of people with these illnesses [12,14].

Not surprisingly, negative mood was also a predictor over time of QOL for both people with MND and those with Parkinson's. These findings are consistent with those of both Greene and Camicioli [31] and Karlsen, Tandberg, Arslan, and Larsen [32], who found a strong association between depression and QOL among older people with Parkinson's. It is interesting that negative mood was not a predictor of QOL for the other two illness groups. Perhaps the variance explained by the level of symptoms may have been shared with negative mood for these two illness groups, and so negative mood did not contribute unique variance to the regression equation.

Low levels of social support satisfaction were a strong predictor of QOL for the MS respondents, but not for the other groups. MS is an unpredictable illness that perhaps requires higher levels of social support satisfaction among these respondents to maintain QOL, compared to

Table 1. Means and standard deviations for all variables.

| | | Quality of life | Mood | Relationship satisfaction | Social support | Symptoms |
|-------------|--------|-----------------|--------------|---------------------------|----------------|-------------|
| | | M (SD) | M (SD) | M (SD) | M (SD) | M (SD) |
| MND | Time 1 | 59.80 (15.14) | 8.34 (5.49) | 4.44 (0.66) | 5.21 (0.86) | 2.66 (0.66) |
| | Time 2 | 59.14 (14.63) | 8.09 (4.90) | 4.54 (0.59) | 5.04 (1.27) | 2.77 (0.51) |
| HD | Time 1 | 50.04 (20.39) | 10.82 (6.82) | 3.86 (0.88) | 4.77 (1.06) | 3.17 (1.01) |
| | Time 2 | 48.77 (20.80) | 13.32 (6.77) | 3.96 (0.86) | 4.56 (1.17) | 3.26 (0.97) |
| MS | Time 1 | 62.28 (14.47) | 6.65 (4.64) | 4.08 (0.87) | 5.00 (1.10) | 2.53 (0.72) |
| | Time 2 | 63.05 (14.38) | 6.75 (4.34) | 4.29 (0.74) | 5.22 (0.78) | 2.42 (0.62) |
| Parkinson's | Time 1 | 60.82 (12.76) | 6.07 (4.26) | 4.35 (0.62) | 4.97 (1.08) | 2.57 (0.72) |
| | Time 2 | 60.06 (14.49) | 6.80 (4.30) | 4.39 (0.64) | 5.04 (0.83) | 2.63 (0.73) |

Table 2. Predictors of quality of life.

| Predictor variable | MND | | | HD | | | MS | | | Parkinson's | | |
|---------------------------|---------|----------|------------------------|---------|----------|------------------------|---------|----------|------------------------|-------------|----------|------------------------|
| | β | <i>p</i> | <i>sr</i> ² | β | <i>p</i> | <i>sr</i> ² | β | <i>p</i> | <i>sr</i> ² | β | <i>p</i> | <i>sr</i> ² |
| Length of illness | -0.10 | 0.43 | | 0.08 | 0.62 | | 0.05 | 0.64 | | -0.26 | 0.01 | 0.06 |
| Symptoms | -0.33 | 0.05 | 0.05 | -0.66 | 0.04 | 0.14 | -0.50 | 0.01 | 0.14 | -0.26 | 0.08 | |
| Mood | -0.47 | 0.01 | 0.11 | 0.01 | 0.98 | | -0.20 | 0.17 | | -0.41 | 0.01 | 0.06 |
| Relationship satisfaction | 0.14 | 0.28 | | 0.00 | 0.98 | | 0.03 | 0.81 | | 0.11 | 0.22 | |
| Social support | 0.07 | 0.59 | | 0.38 | 0.09 | | 0.33 | 0.01 | 0.08 | 0.03 | 0.75 | |

the other illness groups. However, given the demands of the other illnesses, it is surprising that neither social support satisfaction nor relationship satisfaction predicted QOL for these participants. Relationship satisfaction was not a predictor of QOL over time for any of the groups. This is despite the fact that we know that in cross sectional studies support from one's partner is strongly associated with QOL for people with MS [7] and other chronic illnesses [33]. This is a surprising finding, and certainly requires further investigation.

Length of time that they had experienced the illness (but not illness severity) predicted QOL among participants with Parkinson's. People with this neurological illness are frequently older at its onset, and so they may be experiencing the movement into older adulthood, whereas the other respondents are likely to be still in middle adulthood.

Overall, these findings point to the important role played by severity of symptoms in predicting QOL over time for people with neurological illness. This highlights the importance of the biological factors shaping QOL among people with progressive neurological illnesses, although psychosocial factors also play a limited role in predicting QOL. There are some minor differences between the groups in other variables that predict QOL, but the findings suggest that interventions need to focus on managing the severity of the illness in order to improve QOL among people with these disorders.

There are a number of limitations to the current study. The number of participants of some of the illness groups was quite small, and so it is difficult to generalize the findings to all people with these illnesses. In particular, the regressions for the HD group need to be treated with caution due to the small sample size [34]. Participants were recruited from the various illness associations. Although a large percentage of people with these particular illnesses belong to these associations in Australia, and so would be part of the subject pool, it is not possible to generalize the findings to people with these illnesses who choose not to join these associations. There was also a high level of attrition from time 1 to time 2. The study was only conducted over a period of 12 months, and it is possible that changes would occur in the variables over a longer period of time.

However, the findings do demonstrate the areas that need to be targeted in programs to improve the QOL of people with these illnesses, and demonstrate the nature of the differences among people from the different illness groups. Rehabilitation programs need to assist people with these illnesses to better cope with the symptoms, and also the negative mood states that result from having these illnesses. There also needs to be further investigation of the role of social support and support from family, as it was expected that these factors would predict the QOL of people with these neurological illnesses. The results of these studies can then further inform the reha-

bilitation programs for participants with these illnesses.

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