

**Title: Correlates of the personality change judgments of individuals who have MS**

**Running Title: Self-reported personality change in MS**

## **Abstract**

**Objectives:** This is the first study to estimate prevalence of self-reported personality change (PC) in people with multiple sclerosis (MS). Methods developed in traumatic brain injury studies explore physical, cognitive, emotional and social triggers for PC judgments.

**Participants:** 69 MS clinic attendees living with their partner.

**Measures:** Participants rated the degree of PC. Current and pre-MS specific characteristics were rated on semantic differential scales. The Multiple Sclerosis Impact Scale and the MS Neuropsychological Questionnaire quantified perceived symptoms. The Beck Depression Inventory-FastScreen, Hospital Anxiety and Depression Scale assessed emotional distress. Perceived social influences were assessed with the Family Questionnaire, McMaster Assessment Device and the Social Provisions Scale.

**Results:** 54% perceived substantial PC. Current characteristics was a better predictor of PC than perceived behaviour changes. PC was associated with specific characteristics denoting stress reactions, emotional distress, perceived cognitive impairment and poorer family functioning. PC was not significantly related to severity of physical symptoms or social support. This study also suggested that the specific characteristics questionnaire probed at least 2 components of reconstructed identity: PC/Reactivity and Disability.

**Conclusions:** This study raises methodological concerns about measures that simply sum ratings of characteristics related to self-identity. It also proposes possible ways of collaborating with individuals in their efforts to respond constructively to PC and other changes. .

**Keywords:** **Multiple Sclerosis; Personality; Depression; Anxiety; Social Support; Expressed Emotion**

## Introduction

In a review of the symptoms experienced by people with multiple sclerosis (MS), Stathopoulou et al. (1) found that the symptom-profiles of 20%-40% of their sampled cases met the DSM-IV-TR or ICD-10 criteria for personality change. Qualitative studies of people with MS also report specific and global character changes. Individuals have described specific cognitive, behavioural or emotional changes, such as, feeling less confident or more irritable (2-4). Global change in self-concept has been expressed in comments such as, "there's a bit now that's added on that's got MS into it, so that's another facet of my personality", "I'm not the man I used to be" and "I don't think I'll ever be the same person I was" (5,6).

### **Frequency and nature of global personality change judgments**

There appear to be no previous quantitative estimates of the frequency of self-reported global personality change (PC) or of perceived specific changes following MS onset. However, this has been explored in other neurological conditions, most commonly in those sustaining a traumatic brain injury (TBI). For example, individuals frequently (68%-72%) report PC following moderate to severe TBI (7,8). Similarly, 60%-70% of relatives of people sustaining a moderate to severe traumatic brain injury also perceived substantial global PC in their loved ones (9-12).

Several studies of TBI have explored the degree of perceived change on more specific emotional reactions and behaviours. For example, Tyerman and Humphrey (7) asked those sustaining a severe TBI to rate themselves on 20 semantic differential items (e.g., "clumsy-skillful" and "unhappy – happy") on the Head Injury Semantic Differential scale (HISD). Participants rated their perceived position on each adjectival dimension both for their pre-MS selves, and again for their current selves. The present self was perceived to have changed - significantly on 17 of 20 items. Several subsequent studies summed the differences between pre-TBI and current ratings on each of the HISD items in a measure of overall change in these elements of the self-concept (13-15). All studies concluded that total perceived change moved in a negative direction.

Two of the latter studies asked participants if they had changed in themselves or if their personality had changed (7,13). However, neither study attempted to identify characteristics that were associated with perceived global change (i.e., PC), nor did they attempt to correlate global PC with summed specific behaviour scores.

## Correlates of PC

Clinician acknowledgement of client's perceptions that their personality has changed is essential, of course. However, collaborative treatment of PC requires clinician and client agreement on targeting the specific behaviours that lead the client to conclude that their personality has changed. The alternative approach of the clinician telling the client that they have changes that they do not recognise, though sometimes possible, runs the risk of undermining trust in the therapeutic relationship. Improved understanding of the relationship between PC judgments and perceived specific changes is also important since clients and relatives often say that the PC is distressing. Indeed, studies of individuals with TBI have linked perceived global personality changes with emotional distress. For example, global PC after TBI correlated significantly with severity of participants' depression ( $r = 0.70$ ) and negatively ( $r = -0.39$ ) with participants' ratings of PC desirability (8). Similarly, all TBI studies that administered the HISD reported that the changes were in a negative direction, and total current HISD scores correlated highly ( $r=-0.73$ ) with total scores on the Leeds Scales of Anxiety and Depression (16). PC might also be linked with emotional distress in those living with MS, given that a recent meta-analysis estimated an increased prevalence of anxiety (21.9%) and depression (23.7%) in people with MS (17).

Social factors might influence self-reported PC in people who have MS. Certainly, in terms of family influences, extent of criticism close relatives directed towards individuals sustaining a TBI was strongly associated with the degree of PC that the relative perceived (11,12). For example, a social factor, i.e., relatives' criticism, might directly influence the extent to which individuals feel their personality has changed for the worse, perhaps because they internalise the criticism that their close relative expresses towards them. Alternatively, self-reported PC might reflect the development of depression, anger or other behaviours that undermine relationships and so motivate relatives' criticism (19).

Second, poor family adjustment is associated with elevated anxiety and depression in individuals sustaining a TBI (20). If this association also holds for persons with MS, perceived personality changes might include symptoms of emotional distress due to poor family adjustment.

The relationship between perceived social support and perceived PC has not been previously studied. However, lack of social support has been associated with depression in those with MS

(21,22). Accordingly, it would be important to clarify the relationship between PC, depression and social support.

A further hypothesis is that physical symptoms that limit activity, and therefore social participation, significantly alter self-image and contribute to personality change judgments. To our knowledge this has not yet been explored in a MS population, or indeed after acquired brain injury more generally.

Cognitive deficits have been associated with perceived PC after TBI (8,11,23). So, the evidence of a link between PC and cognitive deficits in those with MS is perhaps unsurprising. For example, cognitive deficits associated with MS (24,25) correlated with lowa Scale of Personality Change profiles (26). Moreover, Benedict et al., (27) observed a significant association between executive test scores and NEO Personality Inventory trait ratings by informants (though not participants).

## **Aims**

This paper focuses on the perceptions of people who have MS. It aims:

1. To assess frequency and degree of self-reported global PC following the onset of MS.
2. To explore the degree of perceived change in specific personal characteristics and in the sum of these characteristics following the onset of MS.
3. To identify personal characteristics that lead individuals with MS to conclude that their personality has changed; a corollary being to identify characteristics that might be unrelated to perceived PC.
4. To correlate global PC ratings and specific self-reported behaviours with validated questionnaire measures of physical, cognitive, emotional and social functioning.
5. To examine the possible influence of social context (as measured by criticism, emotional overinvolvement, family functioning and social support) on perceived personality change.

## **Materials and Methods**

### **Participants**

Non-consecutive patients diagnosed as having MS by a Neurologist and attending one of two National Health Service (NHS) MS outpatient clinics were invited to participate. All lived with a partner who had known them for at least 1 year before diagnosis. Exclusion criteria were:

inability to understand questionnaires, current drug or alcohol dependence, learning disability and previous severe psychiatric illness. Of the 156 invited, 69 (44%) participated, 19 (12%) refused, and 68 (44%) did not respond to 3 telephone contact attempts. Participant diagnoses (years from diagnosis, 8.9 SD 8.2) were: benign, 3 (4%); relapse-remitting, 22 (32%); secondary progressive, 24 (35%); primary progressive, 5 (7%); MS diagnosed, type undetermined, 15 (22%). Participant age ranged between 24 and 72 years (49.5 SD 9.4). Forty-two (62%) were female. Most partnerships were long-standing (years, 27.2 SD 10.7). There were 15 (22%) in full-time and 8 (12%) in part-time paid employment. Two (3%) were homemakers. The remaining 42 (64%) were no longer working.

### **Perception of Behavioural Characteristics and Personality Changes**

**Global Personality Change ratings (PC).** Participants were asked to rate the extent of perceived change in overall personality on a 0-3 Likert scale (not at all, a little, a lot, completely). Scores on this scale correlated strongly with well validated questionnaires measuring executive symptoms, anxiety, depression, anger expression and impulsivity in a previous investigation of perceived PC after TBI (8).

The 63 perceiving a change rated its desirability on a scale ranging from 2 to -2 (highly desirable, desirable, desirable in some ways but not others, undesirable or very undesirable).

**Specific characteristics questionnaire.** Participants rated their behaviour on semantic differential items (see figure). This questionnaire was based on the adjectives used in the HISD (7) and Brooks and McKinlay personality adjective checklist (10). Items from the original scale that seemed potentially pejorative (e.g., mature-childish) were excluded. Ten and 4 items were unique to the HISD and the personality adjective checklist, respectively. A further 4 adjectival dimensions were similar, and the personality checklist version was selected. For example, the talkative-quiet option was used in preference to the HISD talkative-withdrawn version as it more closely represented amount of speech produced. The talkative-withdrawn option was potentially more conceptually complex: some respondents might rate themselves as talkative despite being withdrawn at the point of rating because they were depressed, while organic cognitive symptoms might reduce the speech of other participants. Five of the original items were transformed by pairing one pole with a clearer opposite. For example, the HSID emotional-stable item potentially conflates lack of emotion due to neural damage to emotional mechanisms and emotional reactivity to stress. Accordingly, the emotional-unemotional and stable-changeable items were added to the specific characteristics questionnaire. Since the

original scales were devised, there has been increasing appreciation of the impact of brain injury on empathy and social bonding processes. Given the evidence of empathy impairments following various causes of brain damage including MS (28-31), we included items such as concerned about others versus not concerned about others to see if perceived PC might be linked with perceived empathy changes and with social context measures.

Ten dashes separated opposing adjectives. Respondents marked their perceived position on each dimension, the left- and right-most dashes scoring 0 and 9 points, respectively. To minimise a desirability response bias, descriptors the authors deemed more desirable were on the right for half of the items. Participants rated their behaviour before MS onset and then rated their current characteristics. To facilitate statistical analysis and description of differences between pre-MS and current scores on semantic differential items, reverse scoring was applied to those items where mean current scores were found to be lower than mean pre-MS scores.

**Total Current Characteristics score (TCC).** This was the sum of current ratings on the 28 semantic differential items. Tyerman (16) found that the sum of his original current-self HISD ratings correlated highly with degree of total emotional distress on the forerunner of the Hospital Anxiety and Depression Scale.

**Total Change score (TCh).** This was obtained by subtracting pre-MS characteristics scores from current characteristics ratings. The resulting 28 change scores were summed.

[Figure near here]

### **Perceived Physical Symptoms**

The 20 physical items of Multiple Sclerosis Impact Scale (MSIS<sub>phys</sub>) measured the perceived severity of physical symptomatology (32,33). Items, e.g., “How much have you been bothered over the last 2 weeks by stiffness?”, were rated on a 5-point scale: 1 (not at all) - 5 (extremely); total score range = 20-100. Internal consistency (Cronbach  $\alpha \leq 0.91$ ) and test-retest reliability were high for MSIS-29 subscales (intraclass correlation  $\leq 0.87$ ), and mean score was 56 (SD=26.6) in their large normative sample (32). The MSIS<sub>phys</sub> correlates strongly with neurologist ratings on the Expanded Disability Status Scale (EDSS) scores (34).

### **Perceived Cognitive Functioning**

The 15-item Multiple Sclerosis Neuropsychological Questionnaire (MSNQ) (35) quantified perceived frequency of everyday cognitive lapses. Ratings of items, e.g., “Do you forget appointments?”, range from 0 (never, does not occur) to 4 (very often, very disruptive). Total

score range = 0-60. Benedict et al. (36) reported a mean total score of 27.4 (SD=11.9) in their normative sample; Cronbach  $\alpha$  (0.94) and test-retest reliability (0.90) were high.

### **Emotional Adjustment**

The Hospital Anxiety and Depression Scale (37) measured general anxiety. The 7 anxiety items (HADS-A) included, 'I get sudden feelings of panic' over the last week. These were rated 0-3 on a Likert scale. The summed ratings yielded a total score of 0-21. The mean score was 6.7 (SD=4.44) in a consecutive series of MS clinic attendees (38); a cut-off score of  $\geq 8$  indicates the presence of generalised anxiety disorder.

The Beck Depression Inventory – Fast Screen (BDI-FS) (39) is a 7-item self-report inventory. Participants selected one of four statements to best characterise their previous 2 weeks: e.g. selecting 'I do not feel sad' or 'I am so sad or unhappy that I can't stand it' earned 0 or 3 points, respectively. Total score range = 0-21. This screening measure for depression is not confounded with neurological symptoms. Mean total score was 3.6 (SD=3.4) in an MS clinic (40). Total scores of 4-6 and  $\geq 10$  indicate mild and severe depression, respectively (39).

### **Perceived Social Functioning**

Partners completed the Family Questionnaire, a reliable and valid measure of their Expressed Emotion (41). Ten questions measured criticism towards participants (e.g., "He/she does some things out of spite") and 10 questions measured emotional overinvolvement (EOI; e.g., "I tend to neglect myself because of him/her"). Items are rated on a 4-point scale: 1 (never/very rarely) to 4 (very often). High criticism and emotional-overinvolvement cut-off points are  $\geq 23$  and  $\geq 27$ , respectively. Cronbach's  $\alpha$  was  $\geq 0.9$  for criticism and  $\geq 0.79$  for EOI.

The McMaster Family Assessment Device (42) is sensitive to family changes following TBI (20,43). Its 12-item reliable (44) General-Functioning scale (FAD<sub>gfs</sub>) was administered (Cronbach's  $\alpha = 0.86$ ; Split-half coefficient = 0.83). Participants rated items such as, "We feel accepted for what we are" on a 4-point scale depending on strength of agreement. The average item score was used: scores  $\geq 2$  indicate poor adjustment (45).

The Social Provisions Scale (SPS) (46) comprises 6 self-rated 4-item subscales measuring Guidance (advice or information), Reliable Alliance (assurance others can be relied on), Reassurance of Worth (others' recognition of one's value), Nurturance (sense that others rely on one for their well-being), Social Integration (sense of belonging to a group) and Attachment (sense of secure emotional closeness). Reverse scoring of some items produced a total score



(Range=24-96) with higher scores indicating greater social support. The general population mean was 77.8 (SD=8.8) in one study (47), mean total SPS scores being comparable for people with MS (48). Chiu et al. (49) also confirmed reliability (Cronbach's  $\alpha$  was 0.89 for the total score) and construct validity in participants with MS.

### **Procedure**

Most interviews were conducted in participants' homes. Six were conducted by telephone. Participants first rated perceived global personality change (PC). They then completed the Specific characteristics questionnaire before completing the remaining questionnaires. After rating their current MS behaviour, the PC rating was completed. Data were gathered over a 30-month period. The study was approved by the local ethics committee.

### **Statistics**

Data were analysed with SPSS 26. Two-tailed tests were used throughout. An  $\alpha$  of 0.05 was warranted since this study was exploratory. Pearson and Spearman correlation tested strength of association for variables that were and were not normally distributed, respectively. An online calculator tested the significance of differences in the magnitude of correlation coefficients in the same sample (50). Paired t-tests or non-parametric Wilcoxon tests assessed the significance of differences between pairs of related variables. One-way analysis of covariance tested the significance of differences for factors with over 2 levels.

Fourteen of the current semantic differential scores were subjected to an exploratory principal component analysis. All bivariate scatter plots were checked to ensure linearity. Varimax rotation was applied. Excluded variables had loadings greater than 0.40 on 2 factors and/or no loadings greater than 0.60. Inspection of Mahalanobis Distances found no outliers ( $<3$  SD). The principal components analysis was tested for multicollinearity using Bartlett's Test of Sphericity and the Kaiser–Meyer–Olkin test. Scree plots were inspected to identify the number of distinct components. To increase principal component reliability, eigenvalues greater than 1 and above the scree plot "elbow" were compared with component eigenvalues generated in a parallel analysis (51). This Monte Carlo procedure generated eigenvalues from 1000 different sets of random values generated from the number of variables and cases entering the actual analysis. The average eigenvalue for each randomly generated component is equated with the chance level for that principal component. We excluded the components in the actual analysis that had eigenvalues equal to or lower than those produced by the parallel analysis. Cronbach's  $\alpha$  tested consistency of principal component items.

## Results

### Perceived Physical, Cognitive, Emotional and Social Status

Table 1 provides mean scores on measures of perceived physical, cognitive, emotional and social functioning. Mean scores were generally comparable to normative means for MS samples. The correlation was high between MSIS<sub>phys</sub> and the 13 available “gold standard” EDSS scores in this study ( $r=0.77$ ,  $p=0.002$ ). Average MSIS<sub>phys</sub> was virtually identical to the normative MS sample mean. MSNQ scores exceeded the 24-point cut-off for cognitive complaints in 61.4% of this sample. Mean HADS-A was at the  $\geq 8$  cut-off for generalised anxiety. Average BDI-FS was above the  $\geq 4$  mild depression cut-off. The mean FAD<sub>gfs</sub> item score was a little lower than the  $\geq 2$  clinical family dysfunction cut-off. Total SPS in the present sample was at the average level for the general population and in MS samples. 34.3% of partners met the high criticism criterion (score $\geq 23$ ) and 31.4% met the high EOI criterion (score $\geq 27$ ).

[Table 1 near here]

Diagnosis (Benign, Relapse-remitting, Secondary progressive, Primary progressive, Undetermined) was significantly related to MSIS<sub>phys</sub> ( $F_{4,63} = 3.64$ ,  $p=0.01$ ,  $\eta^2=0.19$ ): post hoc Bonferroni tests found the secondary progressive MS group reported more physical symptoms than the Relapse-Remitting group. Diagnosis did not correlate significantly with any other self-report measure.

Apart from a weak negative correlation with HADS-A ( $r = -0.25$ ,  $p = 0.04$ ), years since diagnosis did not correlate with any other variable used in this study.

### Perceived Personality Changes

*Specific characteristics questionnaire.* The figure shows mean pre-MS and current scores on semantic differential items, reverse scoring being applied to those items where mean current scores were lower than mean pre-MS scores. The degree of rightward shift in semantic differential items represents the extent of the perceived change from pre-MS characteristics. The left-most adjective will be used to identify semantic differential items.

Current ratings were evenly distributed across the 0-9 range. However, the distributions of pre-MS scores were highly skewed, 62.1% falling in the low 0-2 range. The high frequency of 0 scores may have arisen because participants' recall of their previous personality was unreliable, probably partly through forgetting since they were endeavouring to remember their

behavioural tendencies an average of 8.9 years previously. Also, low scores mostly report more socially desirable traits, and a “good-old-days” bias may have influenced retrospective semantic differential ratings of pre-MS behaviour (15).

Nevertheless, pre-MS tendencies were meaningfully related to current behaviour. First, Spearman correlations between pre-MS and current scores were significant for 15 items, their left-most adjectives being stable, patient, laid back, unemotional, thinks before acting, tactful, cooperative, affectionate, talkative, friendly, concerned about others, caring, kind, calm and puts self first. Second, 25 asterisked pre-MS and current scores differed significantly.

Despite probable inaccuracies in their opinions about their pre-MS behaviour, they clearly believed they had changed markedly on a range of characteristics. Moreover, these opinions merited further consideration since we assumed that participants’ view that their personality had changed was at least partly based on their beliefs about their pre-MS behaviour.

*Global PC ratings and summary specific characteristics scores.* 8.7% of this sample perceived no global PC. The remainder said their personality had changed a little (37.7%), a lot (43.5%) or completely (10.1%). The change was deemed desirable or highly desirable by 6.4% of those reporting PC. 30.2% felt some changes were desirable and others were not. Most thought it was undesirable (54.0%) or highly undesirable (8.7%).

Despite the concerns about the accuracy of the pre-MS ratings, we predicted PC would correlate more closely with perceived changes than with current ratings. However, PC correlated with 15 change scores and 19 current ratings. Paired comparison of the effect sizes (obtained by squaring correlation coefficients) found that total current (TCC) correlation effect sizes were significantly higher than total change (TCh) effect sizes ( $t=3.52$ ,  $p=0.002$ ). Also, the correlation with PC was significantly ( $z=2.41$ ,  $p=0.016$ ) stronger with TCC ( $r_s=0.57$ ,  $p<0.001$ ) than with TCh ( $r_s=0.41$ ,  $p<0.001$ ).

Many of the significant associations were predicted. For example, as expected, PC correlated significantly with participants’ ratings of current confidence, irritability and happiness. In contrast, PC was not significantly related to some measures. Thus, PC was weakly or not significantly related to the 4 variables with the largest difference scores (Figure). These items are underlined and capitalised in Table 2. This observation is consistent with the view that personality change is one of several components of change in personal identity or the self-concept. It raises the possibility that summing and conflating ratings of many characteristics confounds the contributions of separable components of the changed self-concept.

An exploratory principal component analysis afforded a preliminary investigation of the latter possibility. There were too few cases for confidence that sample and population analyses would yield broadly the same result. However, we believed we could reasonably conduct a preliminary exploration of the possibility that the specific characteristics questionnaire included items reflecting different components of the self-concept. The 14 variables with the largest perceived pre-post differences entered the analysis, allowing 5 cases per variable. Current ratings were used. These were evenly distributed across the 0-9 range,

Three components had eigenvalues greater than 1, but the scree plot levelled off after the second component. Accordingly, a 2-component solution with Varimax rotation was sought. Four items were excluded because their loadings were  $>0.4$  on two principal components or  $<0.59$  on both principal components. A parallel analysis comprised a Monte Carlo analysis on matrices of random values for 8 variables and 69 cases. The eigenvalues of the first two components were higher than the first 2 parallel analysis eigenvalues. The items loading on each component were at least moderately associated with that component in the correlation matrix, and most off-diagonal partial correlation coefficients were low in the anti-image correlation matrix. The Bartlett test of Sphericity (Approximate  $\chi^2 = 256.13$ ,  $df=45$ ,  $p<.001$ ) and the Kaiser-Myer-Olkin measure of sampling adequacy (0.84) confirmed that the correlations did not comprise an identity matrix. Scatterplots met the linearity assumption. Regression component scores were saved for subsequent analyses.

The first component (C1, Reactivity) accounted for 36.8% of the variance. The Reactivity to Stress component loaded highly on 6 variables linked with increased reactivity to stressors: Laidback (0.84), Easy-going (0.82), Even-tempered (0.81), Patience (0.76), Takes things as they come (0.63), Stable (0.59). Cronbach's  $\alpha = 0.85$ .

The second component, C2, accounted for 22.2% of the variance. It loaded on variables associated with ability to do things: Active (0.77), Independent (0.75), Self-confident (0.73), Skilful (0.59). Cronbach's  $\alpha = 0.71$ . This was called the Functional Disability component, as positive scores indicated perceived functional loss.

[Table 2 near here]

### **PC and Specific Characteristics and physical and psychosocial indices**

Scores on validated questionnaires were correlated with PC and composite measures derived from the specific characteristics items to see if the latter indices were meaningfully related to everyday functioning (Table 1). Total current behaviour correlated weakest with physical

functioning and strongest with measures of emotional distress presumably because more of its constituent items were sensitive to emotional distress. The associations with social functioning were weak to moderate. Total perceived change correlated with symptomatology (physical, cognitive and emotional), but not with social measures.

PC correlated with cognitive and emotional symptoms as well as with measures of family functioning (Table 1). Indeed, Table 2 shows that PC correlated most closely with characteristics associated with wellbeing and stress (e.g., self-confidence, satisfaction and irritability). Interestingly, PC had the same correlates apart from  $FAD_{gfs}$  as the Current Reactivity principal component (Table 1), which also loaded on characteristics associated with wellbeing and stress. Unsurprisingly, PC correlated significantly with Current Reactivity ( $r_s = 0.49, p < 0.001$ ).

PC did not correlate significantly with the Functional Disability principal component ( $r_s = 0.16, NS$ ). This component loaded on semantic differential items sensitive to activity, which is compatible with its significant associations with  $MSIS_{phys}$ , cognitive functioning and SPS (Table 1). Moreover, the associates of PC and Functional Disability differed markedly. Thus, though MNSQ and BDI-FS correlated significantly with both, they correlated differently with the 6 remaining indices. That is, PC OR Functional Disability correlated significantly each of the remaining indices. The foregoing results indicate the feasibility of the concept that Current Characteristics questionnaire might be sensitive to 2 aspects of self-identity in people with MS: labelled as PC/Reactivity and Functional Disability in the present report.

### **PC and emotional distress: Potential contributions of cognitive and social influences**

The strongest correlations with PC were with depression, anxiety and Reactivity (Table 1). Accordingly, it was interesting to explore the extent to which the other correlates (cognitive and family factors) might contribute the relationship between PC and distress. Consequently, the association between PC and emotional distress was further analysed in 2 one-way analyses of covariance.

In the first, PC (Absent vs A Little vs A Lot vs Complete) and BDI-FS were the dependent and independent variables, respectively. Table 3 shows that 3 of 4 covariates (MSNQ, EOI and  $FAD_{gfs}$ ) significantly contributed to the relationship between PC and BDI-FS. The PC main effect remained significant after adjustments had been made for cognitive and family variables.

HADS-A was the independent variable and PC the dependent variable in the second one-way ANCOVA. The regression line slope between Criticism and HADS-A was negative for 2 PC

levels and positive for the other 2 levels. So, the assumption of homogeneity of slope was violated and Criticism could not be a covariate. Table 4 shows that MSNQ and  $FAD_{gfs}$  contributed significantly to the relationship between PC and HADS-A, but EOI did not. The PC effect also remained significant after control of cognitive and family variables.

The parallel analysis was performed using TCC, which was converted into a 4-level categorical variable by pooling cases within each quartile. The correlation coefficients between the other variables were virtually identical for the continuous and the categorical TCC versions.

Therefore, the impact of the loss of information on this analysis was probably limited.

Categorical TCC was the dependent variable and BDI-FS was the independent variable in an ANOCOVA. Table 4 shows that MSNQ and Criticism were inappropriate covariates since the independent variable on covariate regression slopes varied across the 4 TCC levels. Severity of physical symptoms and degree of emotional overinvolvement contributed to the relationship between TCC and depression. The main effect remained significant. Regression line slopes varied for most covariates when HADS-A was the independent variable. Adjustments could be appropriately made for the contributions of MSNQ and  $FAD_{gfs}$  and the main effect remained significant (Table 3).

[Table 3 near here]

Table 3 shows that covariates interacted with the factor more often when TCC was the main effect. One possible explanation for this is that TCC comprises more than one identity component where each component has a different relationship with some covariates. Table 1 adds weight to that hypothesis. It shows that the correlates of the Reactivity and Functional Disability principal components were quite different. To explore this hypothesis further, Reactivity and Functional Disability scores were reduced into 4-level categorical variables by pooling scores across quartiles. This enabled a visual comparison of regression line slopes between each covariate and independent variable for Reactivity and Functional Disability. We predicted that ANOCOVA with TCC as the dependent variable would be appropriate where the regression slopes were broadly similar for the 4 Reactivity and 4 Functional Disability cells. Conversely, ANOCOVA would be inappropriate where the direction of the slopes for these putative factors differed. This hypothesis successfully fitted the observation that 5 of the 6 covariates in Table 3 were appropriate. It also predicted the inappropriateness of all 6 potential covariates in Table 3.

## Discussion

This is the first study to quantify the frequency and degree of self-reported personality change after MS onset. Fifty-four percent of the present sample believed that their personality had changed a lot or completely, and another 38% noticed minor change. This estimate is comparable to the 68% of substantial and 23% of minor change in self-reported personality using the same PC measure after moderate to severe TBI (8). Similarly, 72% reported “some change in personality” when Tyerman and Humphreys posed this question (7).

The present participants believed their current behaviour was markedly different from their perceived pre-MS behaviour on characteristics sampled in a semantic differential questionnaire developed from the HISD (7) and the Personality Change Adjective Checklist (10). As in those and subsequent studies using the HISD, participants reported substantial changes that seemed to be mostly negative (i.e., towards being inactive, dependent, irritable and unhappy). Indeed, almost two-thirds of those reporting change rated their PC as highly undesirable or undesirable. However, a few (6.4%) thought that the change had been desirable or highly desirable and the remainder thought the change was desirable in some ways. Indeed, a few changes (e.g., towards thinking before acting and being sensitive) might be perceived as positive by some. Anecdotal clinical experiences and research confirm that individuals sometimes report positive identity changes after brain injury (52,53).

The relationship between perceived PC and change within the wider ranging self-concept is unclear. Accordingly, this study asks, “What characteristics trigger participants’ view that their personality had changed?” Though participants reported marked changes, their PC ratings relied more heavily on their perceived current behaviour than on the self-reported extent of change. Thus, pairwise comparison of the effect sizes of the correlations of PC with current and change ratings found the PC by current rating effect sizes were significantly larger. Moreover, when PC was correlated with Total Current Characteristics (TCC) and Total Change (TCh), the PC by TCC correlation coefficient was significantly larger. Participants’ condition was diagnosed 9 years before on average. The greater influence of opinions about current behaviour on PC ratings presumably arises because memories of recent behaviour are probably more salient than memories of pre-MS behaviour.

An exploratory principal component analysis of semantic differential items found one component loading on 6 characteristics that were all associated with PC. There were too few cases in this study to be confident of agreement between the sample and population solutions.

However, other considerations fit the hypothesis that PC and the first principal component (Reactivity) were related constructs. Thus, there was a moderate correlation between PC and the Reactivity component. PC and Reactivity were both associated with perceived cognitive deficit and family influences, while neither was associated with physical disability or perceived social support. Importantly, PC and Reactivity were both strongly associated with emotional distress and all the Reactivity loadings are of characteristics reflecting reactivity to stress. Interestingly, people who have not sustained a brain injury sometimes consider the changes associated with increased emotional distress to be signs of personality change (54).

A corollary question is, "Are any perceived current or changed characteristics unlikely to contribute to participants' PC ratings?" This study indicates that participants perhaps saw themselves as having become a little less sociable as a person because they perceived relatively small changes in many behaviours important in maintaining and developing social bonds (see figure). However, some of these current characteristics were significantly associated with PC (e.g., cooperative, friendly and affectionate) while others were not (e.g., kind, puts self first and caring). Consequently, the relationship between perceived sociability and PC is unclear from this study. A further study of a larger sample that also included more semantic differential items probing social bonding behaviours might clarify this issue.

Alternatively, future studies might determine the degree of association between PC and elements of sociability. For example, it would be interesting to determine the strengths of the correlations between PC and self-rated empathy as well as a validated and independent measure of empathy.

Interestingly, participants reported most marked negative changes in particularly salient MS features - towards forgetfulness, clumsiness, dependence and inactivity. The correlations between latter characteristics and PC were mostly non-significant. Indeed, an exploratory principal component analysis found a Functional Disability component that loaded on 3 of these characteristics. Functional Disability correlated with physical and cognitive symptoms, depression and decreased social engagement. The pattern of its correlates was quite different from those associated with PC. Unsurprisingly, Functional Disability and PC were not significantly associated. Statements by individuals with MS show that functional limitations impact self-identity, e.g., "MS has made me more dependent on others", "I worry I have become a burden on others" and "I feel more useless since having MS" (2). The foregoing considerations raise the possibility that the heterogeneous characteristics represented in the



Specific Characteristics Questionnaire probes at least 2 identity components: Functional Disability and a distinguishable PC component.

More generally, the statement, "I have changed as a person" arguably expresses the highest level or superordinate concept in the personal identity hierarchy. PC and Functional Disability would be subordinate concepts with specific characteristics at the hierarchy base. On that view, the present Total Characteristics score sums changes across 2 identity change components. Consequently, it is perhaps unsurprising that Total Current Characteristics was significantly associated with all external measures of physical and psychosocial functioning, whereas PC correlated significantly with a subset of external measures. The confounding of 2 identity change components in a single measure clearly impedes our understanding of the components' individual effects. It is suggested that perceived changes in personal identity would be more precisely measured by questionnaires that selectively probe specific reconstructed identity components such as perceived disability, stigmatisation, resilience, empathy, personal growth or personality change.

### **Limitations**

Mean scores of the present sample were broadly comparable with normative means for people with MS on 5 measures (MSIS<sub>phys</sub>, MSNQ, HADS-A, BDI-FS and SPS). Nevertheless, the general applicability of this study is limited by the fact that it only recruited people with partners, the relationships were mostly long-standing, 45% those invited participated, and those unable to complete questionnaires were excluded.

There were too few cases for confidence in the principal component analysis results. However, validity also depends on component meaningfulness (face validity of components and their relationships with external validated measures). Accordingly, we believe these pilot principal component results evidence the feasibility of the concept that the set of current characteristics used in this study probed 2 distinguishable identity components.

Perceived personal growth (52) and benefit finding (55) is reported by individuals with neurological conditions including MS. A third of the present participants felt that their personality had grown in some respects since MS onset. Moreover, participants reported little or no average change in some characteristics. Anecdotal clinical experiences and research evidence indicate that individuals derive a sense of continuity from retained pre-injury features, e.g., memories and retained values (56). This study explored did not explore personal growth or continuity aspects of participants' reconstructed identities.

The present study explores participants' PC perceptions but not their accuracy. Moreover, the accuracy of judgments of some changes in pre-MS behaviour probably decreases with time since diagnosis. Though some public behaviour changes (e.g., the change from being an active worker to becoming unable to work) are probably accurate and contribute to perceived identity change, use of a control group would have provided information about accuracy of semantic differential scores. For example, Reddy et al. (15) compared self-concept ratings of those recently sustaining a TBI with a matched control group. They found that the social desirability of current behaviour ratings of the control and TBI groups did not differ. However, compared with control self-concept ratings 12 months previously, the TBI group rated their pre-injury behaviour as being more socially desirable. In addition to comparing behavioural reports of participants and informants, Obonsawin et al. (57) also used a matched control group in their study of personality change after TBI. They found that negative behaviours were more common in the TBI than in the control group. We plan to provide some clues about the accuracy of the present participants' perceptions in a parallel report on their partners' responses to the same questionnaires.

PC and TCC were not related to time since diagnosis. However, the present study was cross-sectional. Longitudinal studies provide the best way of charting identity reconstruction and emotional reactions to their new identity. For example, longitudinal studies have shown that individuals increasingly include personal growth in their reconstructed identities with time since onset (52,55). Moreover, one factor analytic study distinguished 3 identities following MS onset (58). Sustained identity was possible for those with comparatively minor symptoms. Those with a reactionary identity, for example, tried to prove that they did not need help. People with an integrated identity were comfortable with their disability. Emotional distress was greatest in those with a reactionary identity. It is perhaps likely that self-identity and reactions to it sometimes evolve over time as symptoms increase.

**Clinical Implications**

This study suggests that reducing emotional distress and supporting families might reduce the extent to which individuals living with MS feel that their personality has changed.

Moreover, collaborative treatments require trust which in turn requires clinician appreciation of their client's perspective. When working on identity reconstruction, the clinician needs to understand how clients see themselves. However, clinical criteria for personality change include evidence of irritability, euphoria, apathy, lability and depth of emotional expression, disinhibition, degree of extraversion, agreeableness and conscientiousness (1). In contrast, the present participants linked their PC with irritability and reactivity to threat. Consequently, the

perspectives of clinicians and clients are likely to be aligned when they work together on personality changes linked with increased irritability. Misunderstanding and confusion will arise if the clinician, for example, takes their client's acceptance that their personality has changed as indicating that the client accepts that they have become euphoric. That step would risk breaking the trust essential to collaboration. Similarly, whilst the clinician (and the client's partner) might consider loss of empathy to be a major feature of personality change, their client might feel that they are as caring or have become more caring and sensitive as a result of their experiences. Perceived retention of pre-MS empathy might give the client confidence in their identity (58). That is, they might partly base their belief in their reconstructed identity on their retention of a sense of the importance of being empathetic. Knowing that they retain that value despite a probably reduced capacity to be empathetic would assist. Here, the more effective approach would be to validate the client's appreciation of the importance of empathy for relationships, since highlighting a general reduction in empathy would undermine trust and collaboration. The clinician's next step might be to identify in a couple session a piece of empathic behaviour that client could develop to support their partner and thereby strengthen the couple relationship.

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## **Declaration of interests**

The authors report no declarations of interest.

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Table 1. Perceived physical, cognitive, emotional and social correlates of global PC, TCC, TCh and principal component scores.

PERSONAL IDENTITY MEASURES	M (SD Range)	MSIS <sub>phys</sub>	MSNQ	EMOTIONAL DISTRESS			SOCIAL CONTEXT		
				HADS-A	BDI-FS	Crit	EOI	FAD <sub>gfs</sub>	SPS
<b>GLOBAL PC AND TOTAL SCORES</b>									
PC	1.5 (0.8-0-3)	0.14	0.40 <sup>***</sup>	0.57 <sup>***</sup>	0.55 <sup>***</sup>	0.34 <sup>**</sup>	0.24 <sup>*</sup>	0.27 <sup>*</sup>	-0.19
Total Current Characteristics	127.3 (33.1 27-191)	0.28 <sup>*</sup>	0.46 <sup>**</sup>	0.62 <sup>***</sup>	0.63 <sup>**</sup>	0.39 <sup>***</sup>	0.35 <sup>*</sup>	0.30 <sup>*</sup>	-0.34 <sup>*</sup>
Total Change	54.5 (38.1 -38-148)	0.25 <sup>*</sup>	0.42 <sup>**</sup>	0.56 <sup>**</sup>	0.48 <sup>**</sup>	0.23	0.13	0.15	-0.20
<b>PRINCIPAL COMPONENT SCORES</b>									
C1 (Reactivity)	0.0 (1.0 -2.0-2.0)	.07	.45 <sup>***</sup>	.55 <sup>***</sup>	.43 <sup>**</sup>	.44 <sup>***</sup>	.22	.15	-.12
C2 (Functional Disability)	0.0 (1.0 -2.9-1.5)	.49 <sup>***</sup>	.33 <sup>**</sup>	.22	.38 <sup>***</sup>	.01	.08	.19	-.24 <sup>*</sup>
<b>M</b>		55.2	29.5	7.8	5.2	19.8	23.9	1.8	78.5
<b>(SD Range)</b>		(16.0 20-83)	(11.7 6-57)	(4.7 0-20)	(3.2 0-15)	(5.2 10-29)	(5.3 10-37)	(0.6 1-3.1)	(10.5 52-95)

BDI-FS Beck Depression Inventory – FastScreen; Crit - Criticism; EOI – Emotional Over-involvement; FAD<sub>gfs</sub> – Family Assessment Device (General Functioning Scale); HADS-A – Hospital Anxiety and Depression Scale (Anxiety questions); MSNQ - Multiple Sclerosis Neuropsychological Questionnaire; MSIS<sub>phys</sub> - Multiple Sclerosis Impact Scale (Physical Items); SPS – Social Provisions Scale

\* - p<0.05; \*\* - p<0.01; \*\*\* - p<0.001

Table 2. Mean pre-post MS rating difference and PC correlations with pre-post MS and current ratings

	Current	Pre-post	Difference M (SD)
Self-Confident-Lacks Confidence	.52***	.55***	3.7 (3.6)
Stable-Changeable	.48**	.25*	2.8 (3.0)
Satisfied-Dissatisfied	.45***	.26*	2.5 (3.3)
Patient-Impatient	.45***	.31**	2.4 (3.6)
Interested-Bored	.42***	.34**	2.3 (3.0)
Easy Going-Irritable	.42***	.32**	3.0 (3.1)
Calm-Excitable	.39***	.32**	0.4 (2.9)
Laid Back-Aggressive	.39***	.30*	1.7 (2.7)
Even-Tempered-Quick-Tempered	.39**	.26*	1.9 (3.4)
Happy-Unhappy	.35**	.34**	2.3 (2.8)
Co-Operative-Uncooperative	.32**	.21	1.0 (3.2)
Reasonable-Unreasonable	.30*	.12	1.7 (3.1)
Concerned About Others-Not Concerned About Others	.30*	.13	0.5 (1.7)
Tactful-Tactless	.30*	.22	1.1 (2.2)
Affectionate-Cold	.28*	.27*	0.9 (2.6)
Takes Things As They Come-Worried	.26*	.17	2.4 (3.4)
Talkative-Quiet	.25*	.29*	0.9 (2.4)
Friendly-Unfriendly	.24*	.25*	0.9 (2.6)
<u>MINDFUL-FORGETFUL</u>	.24*	.11	4.2 (2.9)
<u>SKILLFUL-CLUMSY</u>	.23	.24*	4.1 (2.9)
Thinks Before Acting-Impulsive	-.22	.07	1.1 (2.6)
Put Self First-Put Other First	.22	.21	0.3 (2.4)
Kind-Unkind	.16	.31**	0.4 (2.1)
Caring-Unfeeling	.14	.10	0.5 (1.7)
Unemotional -Emotional	.10	.14	1.3 (2.2)
Insensitive-Sensitive	-.07	-.05	1.0 (2.2)
<u>INDEPENDENT-DEPENDENT</u>	.06	-.01	4.3 (3.2)
<u>ACTIVE-INACTIVE</u>	.03	.16	4.8 (3.1)

Table 3. One-way ANOCOVA results: contrasting for the relationship between emotional distress and PC vs total current characteristics main effects

	PC		TOTAL CURRENT CHARACTERISTICS	
	BDI-FS	HADS-A	BDI-FS	HADS-A
<b>Covariates: F<sub>1,61</sub> (p) partial η<sup>2</sup></b>				
MSNQ	4.78 (.03) .07	11.91 (.001) .16	x	10.81 (.002) .15
Criticism	.73 (NS)	x	x	x
EOI	4.95 (.03) .08	.86 (NS)	3.10 (.08) .05	x
FAD <sub>gfs</sub>	5.34 (.02) .08	6.24 (.02) .09	.70 (NS)	9.56 (.003) .13
SPS			.61 (NS)	x
MSIS <sub>phys</sub>			6.44 (.01) .10	x
<b>Main Effect: F (p) partial η<sup>2</sup></b>	4.56 (0.006) 0.18#	7.34 (.0002) .26#	3.88 (.01) .16##	5.81 (.001) .22##

BDI-FS Beck Depression Inventory – FastScreen; Crit - Criticism; EOI – Emotional Over-involvement; FAD<sub>gfs</sub> – Family Assessment Device (General Functioning Scale); HADS-A – Hospital Anxiety and Depression Scale (Anxiety questions); MSNQ - Multiple Sclerosis Neuropsychological Questionnaire; MSIS<sub>phys</sub> - Multiple Sclerosis Impact Scale (Physical Items); SPS – Social Provisions Scale; x – violation of assumption of homogeneity of regression line slope

# - df = 3,63; ## - df = 3,61

