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Adversarial Growth in Patients with Multiple Sclerosis and their Partners: Relationships with Illness Perceptions, Disability and Distress

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Abstract The purpose of this study was to investigate whether patients with multiple sclerosis (MS) and their partners show adversarial growth and to examine which psychological and disability variables contribute to this in patients and their partners. The study also investigated the relationship between growth and distress. Seventy-two patients with MS and their partners provided demographic information and completed measures of posttraumatic growth, illness perceptions, depression, cognitive function and disability. Both patients and partners showed adversarial growth, with patients reporting significantly higher growth than partners. The only significant predictor for patient growth was partner growth, and vice versa. Dissimilarity in illness representations between patients and their partners on the consequences of MS dimension, patient mood and patient growth accounted for significant variance in partner growth. The findings support the idea of a 'communal search for meaning' where patients and their partners experience the trauma of having a chronic illness and subsequently find positive aspects together.

Keywords Multiple sclerosis · Adversarial growth · Illness perceptions

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Introduction

Multiple sclerosis (MS) is a chronic immune mediated disease of the central nervous system (CNS) which affects ~0.1% of Caucasians of north and central European ancestry (Sadovnick et al., 1996; Sharrack & Jenkins, 2010). The onset often occurs in early adult life and it may present with a variety of symptoms including visual impairment, limb weakness, sensory disturbance, balance and postural problems, sphincter dysfunction, pain and fatigue (e.g. Sharrack & Hughes, 1999). Cognitive difficulties are also common and affect memory, attention, executive functioning, visuospatial perception and information processing (e.g. Doraiswamy & Rao, 2004).

Not surprisingly MS is associated with high rates of depression with estimates of lifetime prevalence between 40 and 60% (Mohr & Cox, 2001). High levels of distress have also been reported in caregivers and relatives of people with MS (Figved, Myhr, Larsen, & Aarsland, 2007), and these are commensurate with those found in people caring for individuals with other progressive neurological conditions.

Despite levels of distress and disability the ability of patients with a variety of chronic medical and surgical conditions to construe benefits in coping with such adversity is becoming established in the literature (Affleck & Tennen, 1996; Hefferon, Grealey, & Muthrie, 2009; Joseph & Linley, 2006; Lelorain, Bonnaud-Antignac, & Florin, 2010). Such positive changes tend to be in the areas of perception of the self, philosophy of life and interpersonal relationships (Tedeschi, Park, & Calhoun, 1998; Tedeschi & Calhoun, 2004).

The possible relationship between distress and growth, has been the focus of a number of studies. The majority have reported that greater depression is associated with less growth (e.g. Siegel, Schrimshaw, & Pretter, 2005; Milam, 2004; Katz, Flasher, Cacciapaglia, & Nelson, 2001;

Updegraff, Taylor, Kemeny, & Wyatt, 2002). Other studies have reported that growth is unrelated to depression in MS (Mohr et al., 1999), in psoriasis (Fortune, Richards, Griffiths, & Main, 2005) and in rheumatoid arthritis (Danoff-Berg & Revenson, 2005). Yet others have argued that psychological well-being (Abraído-Lanza Guier & Colón, 1998) and positive mood (Evers et al., 2001) are associated with growth. It remains unclear, therefore, whether distress can be an important spring-board to further development (Tedeschi et al., 1998). The present study aims to further examine whether distress and growth co-exist in MS.

In relation to MS specifically, a number of studies have reported the presence of adversarial growth as a result of the condition. For example, Mohr et al. (1999) reported that finding benefits such as deepening of relationships, enhanced appreciation of life and an increase in spiritual interests were related to adaptive coping strategies such as positive reappraisal and seeking social support. Evers et al. (2001) and Pakenham (2005) also report that acceptance and benefit-finding are associated with more positive outcomes.

Evidence suggests, therefore, that adversarial growth occurs in MS and is adaptive. However, the factors that may be important for growth or those that may inhibit it remain unclear. This is important, as other research has shown that people with MS may show less growth than people with other chronic conditions such as cancer and cardiac disease (Bride et al., 2008). Moreover, while the effects of cognitive difficulties on adjustment have been demonstrated in MS (Jopson & Moss-Morris, 2003), the potential effects of cognitive difficulties on the cognitive-affective processes underpinning adversarial growth is unknown.

It is well documented that patients' perceptions of their illness may be particularly important in the adjustment process. Leventhal and colleagues' (Leventhal, Diefenbach, & Leventhal, 1992; Leventhal et al., 1997) common sense model of illness representations proposes that patients process information about their illness to build complex cognitive representations which guide coping behaviours and can influence psychological outcomes including stress, distress and disability. Illness representations have been shown to affect adaptation to illness in a wide range of conditions (see Hagger & Orbell, 2003), and alongside perceived stress and emotion focused coping, have been shown to be important factors in adjustment to MS (Dennison, Moss-Morris, & Chalder, 2009).

Illness representations held by caregivers/relatives of patients have also been shown to be important not only for adjustment of the relative but also for the patient. Both, Richards et al. (2004) and Heijmans, de Ridder, and Bensing (1999) report that dissimilarity in certain illness representations held by patients and their partners was associated with increased psychological distress, particularly for the partners. Richards et al. (2004) argue that concordance between patients' and their partners' model of illness is important for adjustment. The present study also therefore investigated the role of relatives' illness perceptions in adversarial growth of patients.

The current study had three main aims: to investigate whether patients with MS and their partner showed adversarial growth; to investigate what factors predicted adversarial growth in patients with MS and their partners and to investigate whether there is a relationship between distress and growth.

Method

Design

The study employed a quantitative cross-sectional design. The study was approved by South Sheffield Research Ethics Committee. Questionnaires were administered to patients with MS and their partners to investigate adversarial growth, illness representations, distress, functional impairment, and self-report and partner-report measures of cognitive impairment.

Participants

Patients with relapsing remitting or secondary progressive MS (e.g. Polman et al., 2005) who attended the Sheffield MS Clinic were invited to take part in the study. None had an additional chronic medical condition. Only participants able to complete questionnaires independently were recruited. Partners of patients were contacted via their relative and invited to participate.

Setting

Patients were recruited by three consultant neurologists from an MS Clinic based within a regional neuroscience centre serving a catchment population of 1.8 million people.

Data Collection

In total, 357 questionnaires were given out and 224 returned, giving a response rate of 63%, of which, 90% were completed fully. The final sample comprised 72 pairs of patient and partners.

Measures

Demographic Information

For patients, information was collected on age, gender, marital status, ethnicity, age of leaving full-time education, current employment, type of MS, time since diagnosis, type of treatment received, and relationship to partner. For partners, information was collected on age, gender, marital status, ethnicity, age of leaving full-time education, current employment, relationship to patient and relationship duration.

The Posttraumatic Growth Inventory (PTGI) (Tedeschi & Calhoun, 1996)

The PTGI is a 21-item scale used to measure positive outcomes reported by people who have experienced traumatic events. It includes five factors: (I) Relating to others; (II) New possibilities; (III) Personal strength; (IV) Spiritual change; and (V) Appreciation of life. Each item is scored on a six-point Likert Scale (0 = I did not experience this change as a result of my crisis, 5 = I experienced this change to a very great degree as a result of my crisis). Total scores range from 0 to 105. The PTGI has good internal reliability (full scale $\alpha = .90$; separate subscales $\alpha = .67–.85$) and test re-test reliability of the full scale PTGI is adequate ($\alpha = .71$). In the current study, both patients and their partners were asked to complete the PTGI in terms of their own individual 'growth' as related to MS.

Illness Perception Questionnaire-Revised (IPQ-R) (Moss-Morris et al. 2002)

The IPQ-R was used to assess components of illness representations from Leventhal's Self-Regulatory Model (Leventhal et al., 1992, 1997). Eight components are examined across 38-items: Identity; Timeline (acute/chronic); Consequences; Personal control; Treatment control; Illness coherence; Cyclical timeline perceptions; and Emotional representations. Except for Identity, the items on the IPQ-R are rated by the patient on a five-point Likert scale in terms of degree to which they agree with the statement (1 = strongly disagree, 5 = strongly agree).

All the subscales show good internal reliability, ranging from $\alpha = .079$ to $\alpha = .89$ (Moss-Morris et al., 2002). The IPQ-R also has demonstrated sound discriminant, known group and predictive validity.

An appropriately re-worded version of the IPQ-R (Richards et al., 2004) was given to partners.

Chicago Multi-Scale Depression Inventory (CMDI) (Nyenhuis et al., 1998)

The Mood Scale of the CMDI was used to assess depression. This scale has been specifically designed for use with medical patients and does not include items that have a somatic component. Both patients and partners completed the CMDI in relation to their own distress. The CMDI Mood subscale shows a high ($\alpha = .91$) internal consistency, good convergent and discriminant validity and split-half reliability of .85.

Self-report Expanded Disability Status Scale (EDSS-S) (Bowen, Gibbons, Gianas, & Kraft, 2001)

This is a self-report version of the EDSS (Kurtzke, 1983) which divides functioning into eight systems: pyramidal, cerebellar, sensory, bowel and bladder, visual, brainstem and cerebral. Ambulation is also measured. A total score is derived ranging from 0 (normal neurological exam) to 10 (death due to MS). The EDSS-S strongly correlates with the physician-administered scale, with inter-rater reliability similar to that seen between two physician-administered tests (Bowen et al., 2001).

Multiple Ability Self Report Questionnaire (MASQ) (Seidenberg, Haltiner, Taylor, Hermann, & Wyler, 1994)

The MASQ is a self-report measure assessing five cognitive domains: language, visuo-perceptual, verbal memory, visual memory and attention. Each item is scored on a five-point Likert Scale indicating the degree of difficulty in performing each activity and allows a potential total score between 37 and 185. Concurrent validity has been demonstrated and internal reliability is good (full scale $\alpha = .92$; separate subscales $\alpha = .70$). Both patients and their partners completed the MASQ in relation to the patient's cognitive ability.

Statistical Analysis

Established guidelines were utilised for data screening in relation to accuracy, missing data and assessing normality (see Tabachnick & Fidell, 1996). Descriptive statistics were used to characterise the sample and to examine differences in demographic, medical and psychological variables. *T*-tests were used to examine differences in means, and Pearsons correlation to assess univariate relationships and to provide a means to aid decision-making in relation to the inclusion of variables into the block entry multiple regression analyses. For examination of correlations between dissimilarity in illness perceptions between patients and their partners, Spearmans Rho was utilised.

Results

Demographics

Patients (30 male; 42 female) had a mean age of 47.5 years (SD 10.7). Partners (44 male; 28 female) had a mean age of

48.6 years (SD 10.9). The majority of participants were married (93%). In terms of ethnicity, 97% of patients and partners were white British; with 3% being Irish, Asian and Black or Black British Caribbean. Forty-two percent of patients and 80% of partners were employed at the time of the study.

Fifty-two percent of patients had been diagnosed with relapsing remitting MS, 38% had progressive MS, while the type of MS was undetermined in 10% of cases. Mean time since diagnosis was 10 years and 3 months (SD 9.3, and mean EDSS was 5.17 (SD 1.55).

On the mood subscale of the CMDI, 29 (40.3%) patients and 25 (34.7%) partners scored at or above the clinical cut-off for depression (≥ 23).

Study Variables

Means and standard deviations for each study variable are given in Table 1.

Adversarial Growth

In total 97.2% of patients and 95.8% of partners reported adversarial growth. Patients demonstrated significantly more adversarial growth than partners ($t(142) = 2.24$, $p < .05$).

Univariate Analyses

Correlations were carried out for the 11 study variables with growth (PTGI total scores) for patient and partner variables. Demographic variables were also entered into the correlations but only one (gender of the caregivers) was significantly correlated with patient growth.

For patients, growth (PTGI) was positively correlated with partner growth ($r = .324$, $p = .006$), and with patients' scores on the IPQ-R subscales of personal control ($r = .269$, $p = .022$), identity ($r = .246$, $p = .038$) and timeline cyclical ($r = .269$, $p = .022$). This indicates that for patients, growth is associated with positive beliefs about the controllability of their condition, beliefs about the number of symptoms attributed to the condition and a stronger belief about the cyclical nature of MS. No significant relationship was found between distress and growth in patients ($r = -.134$, $p = .261$).

For partners, significant correlations between partner growth and patient scores on the identity ($r = .329$, $p = .005$) and consequences dimensions ($r = .253$, $p = .032$) of the IPQ-R, indicated that more strongly held beliefs (in the patient) about the number of symptoms attributed to the illness and the negative consequences of MS were associated with higher adversarial growth in partners. Partner total growth score was also positively correlated with patient mood ($r = .311$, $p = .008$), EDSS-S total ($r = .277$, $p = .019$) and partner's score on the identity ($r = .333$, $p = .004$) and emotional representations ($r = .316$, $p = .007$) subscales of the IPQ-R. Commensurate with the findings for patients, no significant relationship was found between distress and Growth in partners ($r = -.004$, $p = .973$).

Multivariate Analyses

Multiple regression analyses were carried out to examine predictors of both patient and partner adversarial growth. A conservative significance level of $p < .01$ was used to determine inclusion in the regression equation. The ratio of number of participants to number of predictor variables

Table 1 Mean and standard deviation scores for each of the study variables for patients and partners

Variable	Patients			Partners		
	Adjusted score[a]	Mean (SD)	Range	Adjusted score[a]	Mean (SD)	Range
PTGI total score	–	43.68 (23.1)	0–89	–	35.57 (20.21)	0–85
Mood (CMDI)	–	20.60 (10.1)	9–45	–	19.35 (9.44)	9–40
EDSS-S total score	–	5.17 (1.55)	3–8	–	–	–
MASQ total	–	72.00 (27.12)	37–130	–	71.43 (29.97)	37–144
Identity	–	9.69 (3.34)	2–16	–	10.29 (3.37)	2–18
Timeline (acute/chronic)	4.56	27.36 (3.34)	18–30	4.53	27.19 (3.87)	13–30
Consequences	3.96	23.74 (4.21)	10–30	3.96	23.78 (4.34)	10–30
Personal control	3.51	17.54 (4.77)	6–29	3.26	16.31 (5.38)	6–30
Treatment control	2.80	14.01 (3.79)	5–21	2.82	14.10 (3.93)	5–24
Illness coherence	2.77	13.83 (4.41)	5–23	2.15	10.75 (3.58)	5–22
Timeline (cyclical)	3.41	13.63 (3.54)	4–20	3.34	13.35 (3.62)	4–20
Emotional representations	3.39	20.35 (4.81)	6–30	3.44	20.62 (5.31)	6–30

[a] Adjusted score for IPQ-R represents mean score per item for each subscale

was approximately 15:1 and the assumptions of linearity, homoscedasticity and normality were met and tolerance values for the predictor variables were all over .20.

For the dependent variable of patient growth, the only predictor variable entered into the equation was partner growth explaining 9.2% of the variance in patient growth ($F = 8.19$, $p = .006$; $\beta = .324$, $p = .006$).

For partner growth, the five predictor variables entered into the equation were: patient growth score, patient scores on the IPQ-R subscale of identity, patient mood, and partner scores on the emotional representations and identity subscales of the IPQ-R. These five predictor variables explained 24% of the variance in partner growth scores ($F = 5.486$, $p = .001$). Of the five independent variables, the only significant predictor was patient growth ($\beta = .302, p = .008$). There was a non significant trend for patient mood ($\beta = .223, p = .07$), and partners emotional representations ($\beta = .195$, $p = .077$).

Dissimilarity in Patient and Partner Illness Perceptions

To compare illness perceptions of patients and partners dissimilarity scores were calculated as described by Heijmans et al. (1999) and Richards et al. (2004). Thus, partner scores for each of the IPQ-R sub-scales were subtracted from the patients' corresponding scores. For the identity sub-scale, partner scores for total number of symptoms relating to MS was subtracted from the patient scores. As it was the magnitude of the difference that was of interest, prior to the correlation and regression analyses using dissimilarity scores, the minus signs were removed from the data.

For patients there was no significant correlation between their growth scores and dissimilarity in illness perceptions between patients and partners. For partners, growth was significantly positively correlated with the dissimilarity score on the consequences dimension ($rho = .332, p < .01$) and on the emotional representations dimension ($rho = .254$, $p < .05$). These positive associations indicate that as the dissimilarity between the scores for patients and their partner increased, the amount of growth reported by the partner also increased on both dimensions.

As none of the dissimilarity scores showed significant correlations at the $p < .01$ level with patient growth, no regression analysis was carried out for those data.

For partner growth, the three predictor variables entered into the equation were: patient growth score, patient mood score and dissimilarity score for the consequences subscale of the IPQ-R. The dissimilarity scores for the consequences subscale were significantly skewed ($Z = 3.82$, $p < .001$). Following square root transformation, the level of skewness was satisfactory ($Z = 1.07$).

The three predictor variables explained 31.1% of the variance in partner's growth ($F = 10.237$, $p = .001$). The variables accounting for the greatest proportion of the variance were: patient mood ($\beta = .359$, $p = .001$), patient Growth ($\beta = .319, p = .003$) and dissimilarity score on the IPQ-R subscale of Consequences ($\beta = .285$, $p = .007$).

Discussion

This is the first study to examine factors that might predict adversarial growth in people with MS and their partners. We found that, 97.2% of patients and 95.8% of partners reported some degree of adversarial growth as a result of MS consistent with previous studies (e.g. Pakenham, 2005).

Patient growth was not associated with demographic variables. Neither was it associated with illness related variables including, type of MS or MS severity, supporting previous research (Lelorain et al., 2010; Katz et al., 2001; Milam, 2004; Mohr et al., 1999; Siegel et al., 2005) and data from the wider illness perceptions literature suggesting that disease severity may be less important for adjustment than an individual's perception of their disease.

We found no significant relationship between growth and duration of illness which is inconsistent with the studies of Evers et al. (2001) and Pakenham (2005). Calhoun and Tedeschi (1998) and Lelorain et al. (2010) have suggested that growth may have a curvilinear relationship with time since diagnosis, peaking at around 1 year and then decreasing. Future research including larger samples across different lengths of time since diagnosis is therefore necessary to examine this more thoroughly.

In relation to illness representations, patient growth was significantly correlated with personal control, number of symptoms attributed to MS and timeline cyclical although none emerged as significant predictors in the final regression equations. It has been suggested that maintaining a sense of control may help offset feelings of helplessness and distress brought on by adverse situations and therefore aid in the restoration of well-being. In the case of MS however, there is only tentative evidence for a moderating effect of perceived control of illness related factors on adjustment (Dennison et al., 2009). Due to the cross-sectional nature of the current study it cannot be determined whether higher perceived control leads to more reports of adversarial growth or whether perceiving benefits as a consequence of a traumatic life event leads to a greater sense of perceived control. Longitudinal studies would be needed to further clarify this issue.

There was a positive association between patient growth and stronger beliefs that MS will be cyclical in nature. Fortune et al. (2005) reported similar findings with patients with psoriasis. While they note that it may initially seem paradoxical that stronger perceptions of threat and harm are associated with greater levels of adversarial growth, Fortune et al. (2005) suggest that patients who adopt a more realistic world-view which acknowledges their own vulnerabilities may be able to find other goals, perspectives and identities in order to build a new assumptive world with meaning. The findings from the present study would be consistent with this argument.

Patient growth was found to be the only significant predictor of partners' growth. This finding is consistent with those of both Pakenham (2005) and Weiss (2004) and lends support to the idea of a 'communal search for meaning' (Pakenham, 2005) where both patients and their partners experience the trauma of having a chronic illness and subsequently find positive aspects of the illness together.

Partners

In partners, we found that the higher the level of neurological impairment reported by the patient and greater impairment on measures of illness representations, the more growth reported by the partner. Similarly, higher partner growth was associated with patients' perceptions of more severe consequences of MS. These findings are interesting, particularly as degree of neurological impairment was not related to the degree of growth in patients. Commensurate with this, Kramer (1993) found that caregivers who provided care to individuals with more limitations in physical functioning reported more caregiving satisfaction. She suggested that caregivers who have more clearly defined care demands find caregiving more rewarding. We also found that higher patient distress was correlated with higher partner growth and it is possible to speculate that higher patient distress may provide a more well defined care demand.

It is interesting that partner's growth was associated with their emotional representations score but not with distress. This may be because the measure of distress taps only low mood, while the emotional representations subscale looks at low mood, anger, worry, anxiety and fear. It is possible that the emotional representations subscale taps into key emotions associated with growth.

Dissimilarity between patients and their partners on the consequences subscale of the IPQ-R emerged as a significant predictor of partner growth. This finding was unexpected based on previous reports that concordance between patients' and partners' model of illness is important in relation to adjustment (Richards et al., 2004). In their review of growth following adversity, Joseph and Linley (2006) postulate that successful coping facilitates disengagement from goals that are now unreachable, and beliefs that are no longer tenable, post-trauma, resulting in decreased emotional distress. It may be that this unexpected result represents a temporal lag between patients and their partner in the stage of disengagement from previously held goals and beliefs. Based on this, dissimilarity in beliefs, particularly about the consequences of MS, may indeed become more comprehensible as a facilitator of adversarial growth for partners.

The finding that patient growth showed no significant correlations with the dissimilarity scores in illness representations may be in line with those of Richards et al. (2004), who found that dissimilarity in illness representations held by patients and their partners with psoriasis had a greater impact on partners than patients.

Relationship Between Distress and Growth

Distress was not significantly associated with growth for either patients or their partners, commensurate with other published findings of (Danoff-Berg & Revenson, 2005; Fortune et al., 2005; Mohr et al., 1999), suggesting that distress and growth do not have to temporally co-exist.

Limitations and Conclusions

Some limitations of this study should be noted. The study included participants from a clinic sample who may not be representative of the wider population of people with MS. There may also have been a bias towards those people choosing to take part in the study being those more likely to report positive changes as a result of their MS. Finally, whilst the nature of the relationship between patient and partner was recorded, the quality of this relationship was unknown. Future studies may decide to include such a measure.

In conclusion, this is the first study to date to investigate the relationship between illness perceptions and adversarial growth in patients with MS and their partners. From a growth perspective, the present results are consistent with the idea of a 'Communal search for meaning' in relation to the diversity in illness expression (the felt sense of unwanted changes in well being) for the individual and their partner. Based on the findings of the present study, it seems important that interventions aimed at facilitating adversarial growth include both the patient and their partner.

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