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Social identity in people with MS: An examination of family identity and mood.

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Practice Points
- Family identity predicts mood in people with MS through social support and connectedness to others.

- The family and the wider social context should be considered in relation to low mood in people with MS.

- Involving the family in the early stages of diagnosis and treatment of MS could increase support for the individual and reduce the high prevalence of mood disorders.
Mood disorders are highly prevalent in people with MS. MS causes changes to a person’s sense of self. The Social Identity Model of Identity Change posits that group membership can have a positive effect on mood during identity change. The family is a social group implicated in adjustment to MS.

Objective

To investigate whether family identity can predict mood in people with MS.

Methods

A cross-sectional survey design (n=123) comprising measures of family identity, family social support, connectedness to others, and mood.

Results

Family identity predicted mood both directly and indirectly through parallel mediators of family social support and connectedness to others.

Conclusion

Family identity predicted mood as posited by the Social Identity Model of Identity Change. Involving the family in adjustment to MS could reduce low mood.
The prevalence of mood disorders in people with multiple sclerosis (MS) is high [1-3], with people with MS experiencing higher rates of depression[1, 4] and anxiety[3, 5] than people with other neurological conditions or the general population. Mood disorders, both anxiety and depression, have a large, negative impact on the lives of people with MS, and both are negatively correlated to quality of life[6]. Therefore considering both anxiety and depression together as an overall indicator of mood could provide greater insight into the negative effects of MS. One explanation for the high prevalence of mood disorders is that the symptoms of MS can cause changes to the way that a person views him or herself[7]. These changes can alter a person’s social identity, resulting in a negative effect on a person’s psychological well-being and mood[8].

However, not everyone who receives a diagnosis of MS experiences the same effects to mood [9]. One explanation for the different responses to the diagnosis of MS can be explained by the Social Identity Model of Identity Change [SIMIC, 10] (Figure 1). The model suggests that maintaining group membership and taking on new identities after a life changing transition can protect against the negative effects of identity change. Maintaining social group identity following a life changing transition can aid in the establishment and adjustment to a new sense of self by providing social support and connectedness to others.

Figure 1: A diagrammatic representation of the Social Identity Model of Identity Change [8, 11]
In line with the SIMIC, maintaining group membership with a pre-established social group, such as the family, could have positive implications for adjustment to MS. The family can aid in identity reconstruction following identity change in response to an MS diagnosis [12]. Identifying with the family group after a diagnosis of MS could provide a source of social support and connectedness to others in line with the SIMIC [10], providing positive effects to a person’s mood.

The SIMIC posits that social support provided by previously established groups can help with the adjustment process. Social support can be defined as “the provision or exchange of emotional, informational or instrumental resources in response to others needs” [13 p. 780]. In addition, social support has been found to facilitate adjustment to MS [14, 15]. Family support has been found to be a salient factor in an individual’s adjustment to MS [14], and is often cited as being the main source of emotional and physical support for people with MS [16].

A diagnosis of MS can cause a change in social identities which can have an effect on mood. Taking on new identities following an identity transition, such as being diagnosed with MS, could have positive effects on mood [17]. Maintaining group membership may lead to connectedness to others, and could contribute to the positive effects on mood.

An investigation into the effects of social identity on mood would allow us to test the SIMIC in an MS population. There were two objectives to this study; firstly, to investigate whether family identity can predict mood in people with MS, secondly, to
test whether this prediction was mediated by social support and connectedness to
others, in line with the SIMIC [10].

Method
The design of the research was a cross-sectional survey. Questionnaires were used to
collect data. Ethical approval for the study was granted by London-Bromley National
Research Ethics Service (NRES) committee (14/LO/0703) and R&D approval by
University Hospitals of Leicester NHS Trust.

Sampling
Participants were identified from two sources: People with MS who had attended the
Neurology Service at University Hospitals of Leicester NHS (National Health
Service) Trust, and people who were recruited via the MS Society’s research
webpage. An a priori power calculation based on three potential predictor variables
and a medium effect size of 0.15 (α=0.05), indicated a total of 119 participants would
be required to provide 0.95 power. However, due to the low expected response rate
with survey methods, the questionnaire was sent to 400 participants. A list of 400 past
and current patients with MS over the age of 18 was compiled from the patient
database at University Hospital of Leicester Neurology Service. Those on the
database had visited the clinic in the 6 months before the list was compiled in August
2014. Invitations to take part and questionnaire packs were sent to a quasi-randomised
(every 4th name on an alphabetical list) sample of 400 people. The packs contained a
participant information sheet that outlined the purpose of the study, why the
participant had been chosen to take part, what the study would entail, any risks to
taking part, who had provided ethical approval for the study, and contact details for
further information.

The other source of participants was through the MS Society website. An online
version of the questionnaire pack was hosted on the research section of the MS
Society website between August 2014 to March 2015. The information on the website
consisted of the same information sent to participants in the questionnaire packs.

**Procedure**

Invitations to take part and questionnaire packs were compiled. We explained to
participants that completing and returning the questionnaire packs would imply
consent. Participants were asked to complete demographic information as well as the
following questionnaires:

1) **Social Identification Scale** [18]: A four-item measure of a person’s identification
   with a social group. The scale was designed so that questions can be adapted to
   focus on the social group under investigation by substituting the section in
   brackets with the social group under investigation; for example, I identify with
   [social group]. The scale was adapted in this study to focus on the family group,
   Participants were asked to rate items such as, “I see myself as a member of the
   family group” on a 7 point Likert scale, from 1 = *Do not agree at all* to 7 = *Agree
   Completely*. Family identity was scored as the sum of all four items with higher
   scores indicating greater family identity.

2) **Multi-dimensional Scale of Perceived Social Support** [19]: A 12-item measure of
   three aspects of a person’s perceived social support: family, friends and
   significant other, with four questions covering each aspect. Participants rated
items on a 7-point Likert scale from 1 = Very strongly disagree to 7 = Very strongly agree. All 12 items were summed to provide an overall score of perceived social support. The scores on the family and significant other subscales were combined to provide an overall score for the family group. Higher scores suggest greater perceived social support.

3) Exeter Identity Transition Scales – New group sub-scale [8]: The new groups subscale is a four-item measure and was used to investigate new groups that participants had engaged with following their diagnosis of MS, whether they have any friends in these groups and whether they identify with these groups. Participants rate items on a 7-point Likert scale from 1 = Do not agree at all to 7 = Agree. Higher scores suggest greater engagement with new groups following a diagnosis of MS.

4) Hospital Anxiety and Depression Scale [20]: A 14-item scale of two aspects of mood (depression and anxiety), with 7 items each. Items are scored on a four-point Likert scale (0-3), with some items reverse scored. The total score of the anxiety and depression subscale was combined to provide an overall measure of mood. Cut-offs indicate normal, borderline, or ‘abnormal’ case. The scale has been validated and has a high level of internal reliability in a sample of people with MS with Cronbach’s alpha for anxiety, depression and total score being .83, .77 & .87, respectively [21]. The Multi-dimensional scale of perceived social support, the Social identification scale and the Exeter identity transition scale, had not been used in MS samples before, therefore, a reliability analysis was conducted to record the internal consistency of the scales used in this study.

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Inclusion Criteria

Participants were invited to participate if they had a diagnosis of MS (including benign, relapsing, remitting, secondary progressive and primary progressive) and were aged 18 or over. Participants attending the MS Clinic at Leicester General Hospital had a confirmed diagnosis of MS and questionnaires were only sent to those over 18. For the online version of the questionnaire, it was clear before taking part that we were interested in people with MS over the age of 18. Due to this sampling technique, there was no way to check this.

Analysis

The data provided by participants was entered into and analysed using SPSS version 21. A non-normal distribution of scores was found on all predictor questionnaires Family Identity new groups (Shapiro-Wilk = <0.05); Family social support (Shapiro-Wilk, = <0.5); new groups (Shapiro-Wilk = <0.05). A normal distribution of scores was found on dependent variable, HADS total score (Shapiro-Wilk = >0.05). Because of this, a bootstrapping mediation analysis was conducted using the PROCESS add on for SPSS[22]. Mediation analysis is a technique used to test how a causal variable has an effect on a dependent variable, using ordinary least squares regression analysis[22]. By conducted a regression analysis on the independent variables associated with the dependent variables, the standardised regression co-efficients were examined to see whether the effect of family identity on mood scores was greater than its indirect effects on social support or willingness to join new social groups. Descriptive statistics were examined and a mediation analysis was conducted.
A parallel mediator model was used to test whether family identity had a positive effect on mood through these mediators. This model assumes that two unrelated variables mediate the relationship between an IV and a DV, in this case, family social support and willingness to engage in new groups both mediate the relationship between family identity and mood. By conducting a regression analysis on the independent variables associated with the dependent variables, the standardised regression co-efficients were examined to see whether the effect of family identity on mood scores was greater than its indirect effects on social support or willingness to join new social groups.

Results

Participants
In total, 123 participants out of 400 invited returned the postal copy of the questionnaire, a response rate of 30.75%. A further 80 participants completed an online version of the questionnaire through the MS Society website, providing a sample of 203 participants.

Data Preparation
Some participants did not complete all the questions before returning the questionnaire. As the questionnaire was completely anonymised, participants could not be contacted to provide the missing information. We decided that for participants missing a single question from any scale, mean substitution based on the participant’s scores on every other item on the questionnaire, was used to enter the missing data. Participants who had missed out more than one question on a questionnaire were excluded from the analysis. Eight participants were removed from the analysis due to
missing data, bringing the total sample to 195. The demographics of the final sample used can be found in Table 1. The mean, standard deviations and correlations of the variables included in the analysis can be found in Table 2.

Table 1: Demographic characteristics of participants.

Table 2: Descriptive statistics of variables included in the mediation analysis

Results of the reliability analysis can be found in Table 3. All scales used in the study had high internal consistency.

Table 3: Internal consistency of scales used.

Family identity was found to be significantly positively correlated with family group social support (p <0.01), willingness to join new groups (p <0.05), and negatively correlated with mood (p <0.01). Family group social support was found to be negatively correlated with mood (p <0.01). Willingness to join new groups was found to be negatively correlated with mood (p <0.01).

Mediation Analysis

From a simple multiple mediator mediation analysis constructed using ordinary least squares regression, family identity influenced mood indirectly through its effect on
social support and willingness to join new groups. As can be seen in Figure 2 and Table 4, participants’ family identity positively predicted levels of social support ($\beta = 0.73, p < .01$). Social support levels were also found to predict mood levels ($\beta = -0.22, p < .01$). Family identity was found to predict willingness to join new groups ($\beta = -0.18, p < .05$). Willingness to join new groups were found to predict mood levels ($\beta = -0.14, p < .05$). A bias-corrected confidence interval for the indirect effect ($\beta = -0.16$) of family identity of mood through social support (based on 5,000 bootstrap samples) was entirely below zero (95% CI’s = -0.27 to -0.08). A bias corrected confidence interval for the indirect effect ($\beta = -0.03$) of family identity of mood through willingness to join new groups (based on 5,000 bootstrap samples) was entirely below zero (95% CI’s = -0.07 to -0.001). There was also evidence that family identity influenced mood independent of the mediating effect of social support and willingness to join new groups ($\beta = 0.19, p < .05$).

Figure 2 Here

Figure 2: Model with regression coefficients.

Table 4 Here

Table 4: Model coefficients.

The results of the mediation analysis showed that family identity predicted mood through the parallel mediators of family social support and willingness to join new groups.
Discussion

In line with previous research showing that people with MS experiencing higher rates of depression [1, 4] and anxiety [3, 5] than people with other neurological conditions or the general population, this was also evident in this study. We found that family identity was negatively associated with mood. Increases in family identity were associated in lower scores on the HADS, which can be interpreted as better overall mood. A mediation analysis further showed that family identity predicted mood through the parallel mediators of family social support and willingness to join new groups.

A number of theoretical implications can be derived from the results. One of the more important implications can be seen in the direct effect of family identity on mood. In line with the SIMIC, identifying with the family group had a positive effect by reducing mood scores. This finding can help explain why the family is often a salient factor in adjustment to MS, as identifying with the family group appears to be protect people with MS from the harmful effects of identity change following the life changing transition of being diagnosed with the disease.

Social support from the family group and willingness to join new groups was found to mediate the relationship between family identity and mood. Previously established identities provide a basis for drawing social support and a good platform for people to establish new identities that are compatible and integrated with old identities to enhance identity continuity [11]. The mediating effects in this model have shown that family identity has an effect on mood through the mediators of increased family social support.
support and increased willingness to join new groups, in line with the SIMIC [11], whilst this has been implicated in adjustment to MS, it has only so far been investigated in qualitative studies [16].

Whilst future, longitudinal, research is still needed, the results of this study could have clinical implications. Involving the family in the early stages of diagnosis and treatment of MS could increase social support for the person with MS, potentially reducing the negative effects of MS on mood. Similarly, educating family members on how to successfully provide social support, could lead to the person with MS feeling greater identification with the family group and a reduction in low mood.

The main strengths of this study was the size of the sample used. Using both an NHS MS database and an online questionnaire resulted in a large number of people taking part in the study. A limitation of this study is the use of the Exeter Identity Transition Scales to measure willingness to join new groups. There are no established questionnaires to measure connectedness to others and because of this the decision was made to measure attempts to join newly established groups, using the new group’s sub-scale of the Exeter Transition Scales. Whilst using an NHS MS database resulted in a larger sample size, this may have included more people in the early stages of the disease, complicating the validity of the sample. The return rate of completed questionnaires was 37.75%. In an attempt increase the size of the sample, an online version of the questionnaire was created. The online version of the questionnaire was hosted on the research section of the MS Society website but the response rate to this version is unknown.
There are several implications of this study. Firstly, family support in response to MS diagnosis may be more beneficial than is currently understood. A number of UK MS charities provide bibliotherapy on the use of the family in support following diagnosis [23, 24]. Involving the family in the early stages of diagnosis and treatment of MS could increase support for the individual and reduce the high prevalence of mood disorders. Secondly, family identity and family social support are highly correlated constructs. Whilst the direction of the association cannot be established by simply examining a correlation, teaching family members on how to successfully provide social support to the family member with MS could lead to greater identification with the family group and a reduction in low mood. However, this would need to be examined in further research. Thirdly, after increasing support from the family group and after a period of adjustment, families could be taught how to encourage participation in other social groups. By taking part in new groups, the person with MS may be able to further incorporate their identity continuity by establishing new identities that are compatible and integrated with the family identity.

A longitudinal investigation of the effects of family identity will be required to further understand the effects of previously established social groups on the reduction of the negative effects of identity change.

**Disclosure Statement**

Alex B. Barker, PhD studentship was funded by the MS Society (966/12).

**References**


Figure 1: A diagrammatic representation of the Social Identity Model of Identity

Table 1: Demographic characteristics of participants.

Table 2: Descriptive statistics of variables included in the mediation analysis.

Table 3: Internal consistency of scales used.

Figure 2: Model with regression coefficients.

Table 4: Model coefficients.
Table 1: Demographic characteristics of participants.

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<th>Mean (Standard Deviation)</th>
<th>Range</th>
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<td>23 - 85 years</td>
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<td>5 – 10 Years</td>
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<td>Mood</td>
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<td>7.97</td>
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Table 3: Internal consistency of scales used.

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<tr>
<td>Multi-dimensional Scale of Perceived Social Support (Family and significant other)</td>
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<td>Social Identification Scale (Family)</td>
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<td>Exeter Identity Transition Scale (New groups sub-scale)</td>
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<td>------------</td>
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<td></td>
<td>Path</td>
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<tr>
<td>X Family Identity</td>
<td>A¹</td>
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<td>M¹ Family Social Support</td>
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<td>M² Willingness to join new groups</td>
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<td>CONSTANT</td>
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<td>R² = 0.24</td>
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<td>F (1, 191) = 46.47, p = &lt;0.01</td>
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Table 4: Model Coefficients
Figure 1: A diagrammatic representation of the Social Identity Model of Identity Change [8, 11]
Figure 2: Model with regression coefficients.

Family identity

Family social support

Willingness to join new groups

Mood

$A^1$  
$\beta = 0.73, $  
$p = < .01$

$B^1$  
$\beta = 0.18, $  
$p = .034$

$A^2$  
$\beta = -0.22, $  
$p = < .001$

$B^2$  
$\beta = -0.14, $  
$p = .021$

$C$  
$\beta = -0.19, $  
$p = .043$