

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

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22 **Practice Points**

- 23       • Family identity predicts mood in people with MS through social support and  
24           connectedness to others.
- 25       • The family and the wider social context should be considered in relation to  
26           low mood in people with MS.
- 27       • Involving the family in the early stages of diagnosis and treatment of MS  
28           could increase support for the individual and reduce the high prevalence of  
29           mood disorders.

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47   **Abstract**

48 Background

49 Mood disorders are highly prevalent in people with MS. MS causes changes to a  
50 person's sense of self. The Social Identity Model of Identity Change posits that group  
51 membership can have a positive effect on mood during identity change. The family is  
52 a social group implicated in adjustment to MS.

53 Objective

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

55 Methods

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

58 Results

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

61 Conclusion

62 Family identity predicted mood as posited by the Social Identity Model of Identity  
63 Change. Involving the family in adjustment to MS could reduce low mood.

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72 **Introduction**

73 The prevalence of mood disorders in people with multiple sclerosis (MS) is high [1-  
74 3], with people with MS experiencing higher rates of depression[1, 4] and anxiety[3,  
75 5] than people with other neurological conditions or the general population. Mood  
76 disorders, both anxiety and depression, have a large, negative impact on the lives of  
77 people with MS, and both are negatively correlated to quality of life[6]. Therefore  
78 considering both anxiety and depression together as an overall indicator of mood  
79 could provide greater insight into the negative effects of MS. One explanation for the  
80 high prevalence of mood disorders is that the symptoms of MS can cause changes to  
81 the way that a person views him or herself[7]. These changes can alter a person's  
82 social identity, resulting in a negative effect on a person's psychological well-being  
83 and mood[8].

84

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

93

94 Figure 1: A diagrammatic representation of the Social Identity Model of Identity  
95 Change [8, 11]

96 Figure 1 Here

97

98 In line with the SIMIC, maintaining group membership with a pre-established social  
99 group, such as the family, could have positive implications for adjustment to MS. The  
100 family can aid in identity reconstruction following identity change in response to an  
101 MS diagnosis [12]. Identifying with the family group after a diagnosis of MS could  
102 provide a source of social support and connectedness to others in line with the SIMIC  
103 [10], providing positive effects to a person's mood.

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

113

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

119

120 An investigation into the effects of social identity on mood would allow us to test the  
121 SIMIC in an MS population. There were two objectives to this study; firstly, to  
122 investigate whether family identity can predict mood in people with MS, secondly, to

123 test whether this prediction was mediated by social support and connectedness to  
124 others, in line with the SIMIC [10].

125

## 126 **Method**

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

131

### 132 Sampling

133 Participants were identified from two sources: People with MS who had attended the  
134 Neurology Service at University Hospitals of Leicester NHS (National Health  
135 Service) Trust, and people who were recruited via the MS Society's research  
136 webpage. An *a priori* power calculation based on three potential predictor variables  
137 and a medium effect size of 0.15 ( $\alpha=0.05$ ), indicated a total of 119 participants would  
138 be required to provide 0.95 power. However, due to the low expected response rate  
139 with survey methods, the questionnaire was sent to 400 participants. A list of 400 past  
140 and current patients with MS over the age of 18 was compiled from the patient  
141 database at University Hospital of Leicester Neurology Service. Those on the  
142 database had visited the clinic in the 6 months before the list was compiled in August  
143 2014. Invitations to take part and questionnaire packs were sent to a quasi-randomised  
144 (every 4<sup>th</sup> name on an alphabetical list) sample of 400 people. The packs contained a  
145 participant information sheet that outlined the purpose of the study, why the  
146 participant had been chosen to take part, what the study would entail, any risks to

147 taking part, who had provided ethical approval for the study, and contact details for  
148 further information.

149

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

154

#### 155 Procedure

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

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

169 2) Multi-dimensional Scale of Perceived Social Support [19]: A 12-item measure of  
170 three aspects of a person's perceived social support: family, friends and  
171 significant other, with four questions covering each aspect. Participants rated

172 items on a 7-point Likert scale from 1 = *Very strongly disagree* to 7 = *Very*  
173 *strongly agree*. All 12 items were summed to provide an overall score of  
174 perceived social support. The scores on the family and significant other subscales  
175 were combined to provide an overall score for the family group. Higher scores  
176 suggest greater perceived social support.

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

184 4) Hospital Anxiety and Depression Scale [20]: A 14-item scale of two aspects of  
185 mood (depression and anxiety), with 7 items each. Items are scored on a four-point  
186 Likert scale (0-3), with some items reverse scored. The total score of the anxiety and  
187 depression subscale was combined to provide an overall measure of mood. Cut-offs  
188 indicate normal, borderline, or ‘abnormal’ case. The scale has been validated and has  
189 a high level of internal reliability in a sample of people with MS with Cronbach’s  
190 alpha for anxiety, depression and total score being .83, .77 & .87, respectively  
191 [21]. The Multi-dimensional scale of perceived social support, the Social identification  
192 scale and the Exeter identity transition scale, had not been used in MS samples before,  
193 therefore, a reliability analysis was conducted to record the internal consistency of the  
194 scales used in this study.

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197 Inclusion Criteria

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

205

206

207 Analysis

208 The data provided by participants was entered into and analysed using SPSS version  
209 21. A non-normal distribution of scores was found on all predictor questionnaires  
210 Family Identity new groups (Shapiro-Wilk =  $<0.05$ ); Family social support (Shapiro-  
211 Wilk, =  $<0.5$ ); new groups (Shapiro-Wilk =  $<0.05$ ). A normal distribution of scores  
212 was found on dependent variable, HADS total score (Shapiro-Wilk =  $>0.05$ ). Because  
213 of this, a bootstrapping mediation analysis was conducted using the PROCESS add on  
214 for SPSS[22]. Mediation analysis is a technique used to test how a causal variable  
215 has an effect on a dependent variable, using ordinary least squares regression  
216 analysis[22]. By conducted a regression analysis on the independent variables  
217 associated with the dependent variables, the standardised regression co-efficients  
218 were examined to see whether the effect of family identity on mood scores was  
219 greater than its indirect effects on social support or willingness to join new social  
220 groups. Descriptive statistics were examined and a mediation analysis was conducted.

221

222 A parallel mediator model was used to test whether family identity had a positive  
223 effect on mood through these mediators. This model assumes that two unrelated  
224 variables mediate the relationship between an IV and a DV, in this case, family social  
225 support and willingness to engage in new groups both mediate the relationship  
226 between family identity and mood. By conducting a regression analysis on the  
227 independent variables associated with the dependent variables, the standardised  
228 regression co-efficients were examined to see whether the effect of family identity on  
229 mood scores was greater than its indirect effects on social support or willingness to  
230 join new social groups.

231

## 232 **Results**

### 233 Participants

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

238

### 239 Data Preparation

240 Some participants did not complete all the questions before returning the  
241 questionnaire. As the questionnaire was completely anonymised, participants could  
242 not be contacted to provide the missing information. We decided that for participants  
243 missing a single question from any scale, mean substitution based on the participant's  
244 scores on every other item on the questionnaire, was used to enter the missing data.  
245 Participants who had missed out more than one question on a questionnaire were  
246 excluded from the analysis. Eight participants were removed from the analysis due to

247 missing data, bringing the total sample to 195. The demographics of the final sample  
248 used can be found in Table 1. The mean, standard deviations and correlations of the  
249 variables included in the analysis can be found in Table 2.

250

251 Table 1: Demographic characteristics of participants.

252 *Table 1 Here*

253

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

255 *Table 2 Here*

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

259

260 Table 3: Internal consistency of scales used.

261 *Table 3 Here*

262

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

268

269 Mediation Analysis

270 From a simple multiple mediator mediation analysis constructed using ordinary least  
271 squares regression, family identity influenced mood indirectly through its effect on

272 social support and willingness to join new groups. As can be seen in Figure 2 and  
273 Table 4, participants' family identity positively predicted levels of social support ( $\beta =$   
274 0.73,  $p = < .01$ ). Social support levels were also found to predict mood levels ( $\beta = -$   
275 0.22,  $p < .01$ ). Family identity was found to predict willingness to join new groups ( $\beta$   
276 = -0.18,  $p = < 0.05$ ). Willingness to join new groups were found to predict mood levels  
277 ( $\beta = -0.14$ ,  $p = < 0.05$ ). A bias-corrected confidence interval for the indirect effect ( $\beta$   
278 = -0.16) of family identity of mood through social support (based on 5,000 bootstrap  
279 samples) was entirely below zero (95% CI's = -0.27 to -0.08). A bias corrected  
280 confidence interval for the indirect effect ( $\beta = -0.03$ ) of family identity of mood  
281 through willingness to join new groups (based on 5,000 bootstrap samples) was  
282 entirely below zero (95% CI's = -0.07 to -0.001). There was also evidence that  
283 family identity influenced mood independent of the mediating effect of social support  
284 and willingness to join new groups ( $\beta = 0.19$ ,  $p < .05$ ).

285

286 *Figure 2 Here*

287 Figure 2: Model with regression coefficients.

288

289 *Table 4 Here*

290 Table 4: Model coefficients.

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292

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

296

297

298 **Discussion**

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

307

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

315

316 Social support from the family group and willingness to join new groups was found to  
317 mediate the relationship between family identity and mood. Previously established  
318 identities provide a basis for drawing social support and a good platform for people to  
319 establish new identities that are compatible and integrated with old identities to  
320 enhance identity continuity [11]. The mediating effects in this model have shown that  
321 family identity has an effect on mood through the mediators of increased family social

322 support and increased willingness to join new groups, in line with the SIMIC [11],  
323 whilst this has been implicated in adjustment to MS, it has only so far been  
324 investigated in qualitative studies [16].

325

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

332

333 The main strengths of this study was the size of the sample used. Using both an NHS  
334 MS database and an online questionnaire resulted in a large number of people taking  
335 part in the study. A limitation of this study is the use of the Exeter Identity Transition  
336 Scales to measure willingness to join new groups. There are no established  
337 questionnaires to measure connectedness to others and because of this the decision  
338 was made to measure attempts to join newly established groups, using the new  
339 group's sub-scale of the Exeter Transition Scales. Whilst using an NHS MS database  
340 resulted in a larger sample size, this may have included more people in the early  
341 stages of the disease, complicating the validity of the sample. The return rate of  
342 completed questionnaires was 37.75%. In an attempt increase the size of the sample,  
343 an online version of the questionnaire was created. The online version of the  
344 questionnaire was hosted on the research section of the MS Society website but the  
345 response rate to this version is unknown

346

347 There are several implications of this study. Firstly, family support in response to MS  
348 diagnosis may be more beneficial than is currently understood. A number of UK MS  
349 charities provide bibliotherapy on the use of the family in support following diagnosis  
350 [23, 24]. Involving the family in the early stages of diagnosis and treatment of MS  
351 could increase support for the individual and reduce the high prevalence of mood  
352 disorders. Secondly, family identity and family social support are highly correlated  
353 constructs. Whilst the direction of the association cannot be established by simply  
354 examining a correlation, teaching family members on how to successfully provide  
355 social support to the family member with MS could lead to greater identification with  
356 the family group and a reduction in low mood. However, this would need to be  
357 examined in further research. Thirdly, after increasing support from the family group  
358 and after a period of adjustment, families could be taught how to encourage  
359 participation in other social groups. By taking part in new groups, the person with MS  
360 may be able to further incorporate their identity continuity by establishing new  
361 identities that are compatible and integrated with the family identity.

362

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

366

### 367 **Disclosure Statement**

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369

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

441 Change [8, 11]

442 Table 1: Demographic characteristics of participants.

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

444 Table 3: Internal consistency of scales used.

445 Figure 2: Model with regression coefficients.

446 Table 4: Model coefficients.

Table 1: Demographic characteristics of participants.

	Mean (Standard Deviation)	Range
Age in years	48.19 (11.02)	23 - 85 years
	Frequency	Percentage
<u>Time Since Diagnosis</u>		
Less than 1 year	10	5.1
1 – 3 Years	37	19.1
3 – 5 Years	24	12.3
5 – 10 Years	39	20
10 – 15 Years	45	23.1
More than 15 Years	37	19
Missing	3	1.5
<u>Gender</u>		
Men	50	25.6
Women	141	72.3
Missing	4	2.1
<u>Type of MS</u>		
Relapsing Remitting	102	52.3
Primary Progressive	34	17.4
Secondary Progressive	42	21.5
Benign	10	5.1
Missing	7	3.6
<u>Relationship Status</u>		
Married / Partner	142	72.8
Divorced / Separated / Widowed	26	13.3
Single	23	11.8
Missing	4	2.1
<u>Living Arrangements</u>		
Living with Partner	118	60.5
Living Alone	24	12.3
Living with Family	35	17.9
Living with Friends	2	1
Other	12	6.2
Missing	4	2.1
<u>Ethnicity</u>		
White	169	86.6
Black	5	2.5
Asian	10	5.1
Mixed	3	1.5
Any Other	4	2.1
Missing	4	2.1

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

Variable	Mean	Standard Deviation	Family Identity		Family group social support		Willingness to join new groups	
			Correlation Coefficient	Significance	Correlation Coefficient	Significance	Correlation Coefficient	Significance
Family Identity	22.35	7.13			0.50	p=<0.001	0.16	p=0.03
Family group social support	42.96	10.46	0.50	p=<0.001			0.12	p=1.00
Willingness to join new groups	13.72	8.99	0.16	p=0.03	0.12	p=1.00		
Mood	17.91	7.97	-0.33	p=<0.001	-0.39	p=<0.001	-0.21	p=<0.001.

Table 3: Internal consistency of scales used.

Scale	Reliability (Cronbach's $\alpha$ )
Multi-dimensional Scale of Perceived Social Support (Family and significant other)	.91
Social Identification Scale (Family)	.96
Exeter Identity Transition Scale (New groups sub-scale)	.95
HADS Total Score	.88

Table 4: Model Coefficients

	Consequent											
Antecedent	M <sup>1</sup> Family Social Support				M <sup>2</sup> Willingness to join new groups				Y Mood			
	Path	Co-efficient.	SE	p	Path	Co-efficient.	SE	p	Path	Co-efficient	SE	p
X Family Identity	A <sup>1</sup>	0.73	0.11	0.00	B <sup>1</sup>	0.18	0.08	0.03	C	-0.19	0.09	0.04
M <sup>1</sup> Family Social Support	-	-	-	-	-	-	-	-	A <sup>2</sup>	-0.22	0.06	0.00
M <sup>2</sup> Willingness to join new groups	-	-	-	-	-	-	-	-	B <sup>2</sup>	-0.14	0.06	0.02
CONSTANT	I <sup>1</sup>	26.53	2.62	<0.01	I <sup>2</sup>	9.51	5.03	<0.01	I <sup>3</sup>	33.43	2.43	0.00
	R <sup>2</sup> = 0.24				R <sup>2</sup> = 0.02				R <sup>2</sup> = 0.20			
	F (1, 191) = 46.47, p = <0.01				F (1, 191) = 4.56, p = 0.03				F (3, 189) = 16.56, p = <0.05			

Figure 1: A diagrammatic representation of the Social Identity Model of Identity Change [8, 11]

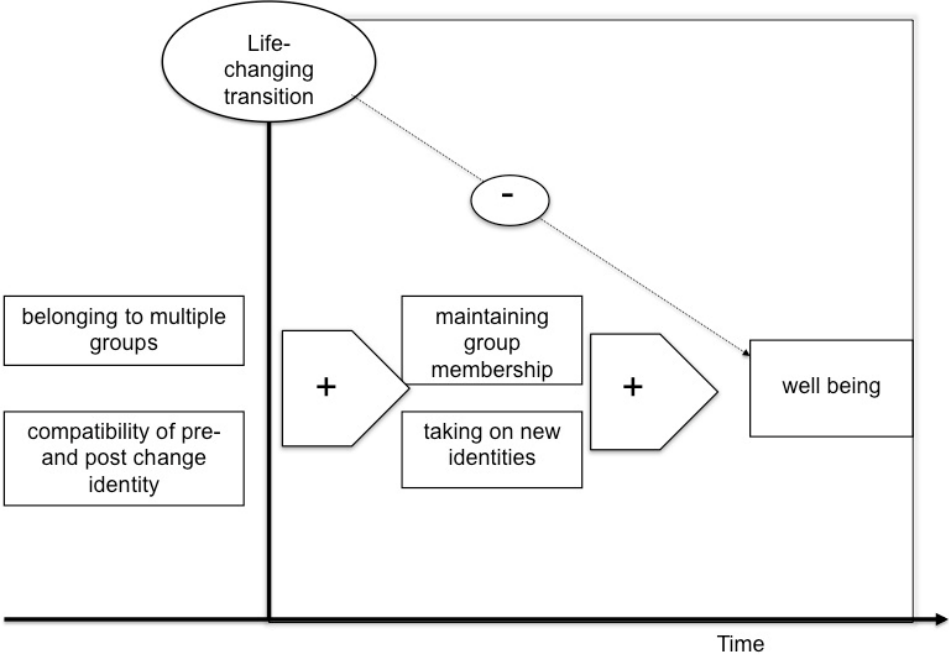


Figure 2: Model with regression coefficients.

