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Parents' expressed emotion and mood, rather than their physical disability are associated with adolescent adjustment. A longitudinal study of families with a parent with multiple sclerosis.

Bogosian, A., Hadwin, J., Hankins, M., Moss-Morris, E.

Abstract

Objective. This study investigated the impact of the severity of parental multiple sclerosis, parents' expressed emotion and psychological well-being on offspring's psychological difficulties.

Design: A longitudinal study including baseline and 6-month follow-up data collected from parents and children.

Subjects: Adolescents (n=75), their parents with multiple sclerosis (n=56) and the partner without multiple sclerosis (n=40)

Main measures: Parents completed the Hospital Anxiety and Depression Scale and the Five Minutes Speech Sample, a standardised interview of expressed emotion towards their child. Parents with multiple sclerosis also completed the Expanded Disability Status Scale, a measure of illness severity. Adolescents completed the Strength and Difficulties Questionnaire, a self-report measure of psychological difficulties.

Results: Higher depression scores of the parents with multiple sclerosis at baseline correlated with increased adolescents' internalising symptoms at 6-month follow-up ($\gamma_{\text{dep}}=0.31$, $p=.004$). Higher expressed emotion scores of parents with multiple sclerosis at baseline were associated with increased

adolescent externalising symptoms at 6-month follow-up ($\gamma_{EE}=4.35$, $p=.052$).

There was no direct effect of severity, duration or type of multiple sclerosis on adolescents' adjustment at baseline or follow-up.

Conclusions: Emotional distress and expressed emotion in parents with multiple sclerosis, rather than the severity and type of multiple sclerosis had an impact on adolescents' psychological difficulties.

Keywords: adolescent children; multiple sclerosis; parents; emotional distress

Introduction

Having a parent with a health problem can be emotionally challenging for children and adolescents (1). Research in multiple sclerosis suggests that illness exacerbations are linked with a decrease in maternal affection towards their children (2), and parental functional impairment is associated with lower child's satisfaction with life (3). In addition, cross-sectional studies in parental multiple sclerosis showed that family dysfunction, parental depressive symptoms and lack of social support are associated with child's externalising symptoms, such as aggression, and delinquent behaviour (4, 5). On the other hand, the severity of multiple sclerosis is associated with children's internalising symptoms, such as anxiety, depression and withdrawal (5). The only longitudinal study in this area showed that parental multiple sclerosis severity and physical disability directly predicted increased levels of stigma and greater role distribution within families, but exhibited no direct relationship with children's well-being (6). It is still unclear whether the severity or the psychological consequences of the illness are most important for understanding emotional distress in offspring.

Studies in parental multiple sclerosis have focused on self-reports of family relationship factors (7). Another way of exploring the emotional relationship between children and their parents is the measurement of expressed emotion. Research shows that high parental expressed emotion is associated with greater internalising (8, 9) and externalising (10, 11) symptoms in offspring. To the best of our knowledge, there is no study investigating the role of parental expressed emotion in the context of parental illness.

Most of the research to date has focused on the parent with multiple sclerosis. A recent qualitative study suggested that the well partner may play an important role in moderating the impact of parental multiple sclerosis by providing practical help around the house and emotional support (12). Two quantitative studies in multiple sclerosis showed that children's psychosocial problems (based on parental reports) positively correlated with depression scores of the well parent (4, 5). Here, we will use adolescents' self-reports to explore the impact of well parents on adolescents' adjustment.

Most studies in this research area, have failed to separate older and younger children in their analysis. The mixed-age analysis is problematic because the way children adapt to parental illness varies across development (13). Also, in multiple sclerosis, adolescents might be at increased risk for internalising and externalising symptoms compared to younger children (7). For these reasons, this study focuses on the impact of parental multiple sclerosis in adolescent children.

We hypothesised that greater illness severity, progressive types of multiple sclerosis and longer duration of the illness at baseline will be associated with higher adolescent reports of internalising and externalising symptoms both cross-sectionally and over time. In addition, we predicted that increased anxiety and depression symptoms in both parents at baseline would be positively associated with adolescents' internalising and externalising symptoms both cross-sectionally and longitudinally. Finally, we expected that parents' expressed emotion towards the adolescent at baseline would be

important in understanding symptoms of internalising and externalising symptoms in adolescents cross-sectionally and longitudinally.

Methods

The Southampton University Ethics Committee and Research Governance (Ref: 917/6241/AB5) and the Southampton & South West Hampshire Research Ethics Committee (Ref: 09/H0502/30) approved the project prior to recruitment. Multiple sclerosis nurses and neurologists from two hospitals in UK gave out information packs to parents with multiple sclerosis. The packs included information sheets (one version for adolescents and one for parents), consent and assent forms and the researchers' contact details. We also recruited participants through adverts on Multiple Sclerosis Society websites.

We recruited families who had a parent with multiple sclerosis and an adolescent child between 12 and 19 years old. The adolescent and at least one parent had to agree to take part in this study in order to include them. We recruited 49 families through the hospitals and 26 families through the Multiple Sclerosis Society websites.

A longitudinal design was used. Participants completed the same set of questionnaires at baseline and six months. The first author arranged a telephone interview with the parents at baseline in order to obtain the expressed emotion assessment. Adolescents, who returned their questionnaire pack, received a £5 voucher as a thank you at each time point.

Parents and adolescents completed a demographics questionnaire. Parents with multiple sclerosis completed the Expanded Disability Status Scale, which provides a measure of the severity of multiple sclerosis symptoms and correlates well with physician rated scores (14). Expanded Disability Status Scale assesses mobility, cognitive impairment, visual disturbances and bladder dysfunction. The total score can range from 0 (normal neurological examination) to 10 (death due to multiple sclerosis). The first author scored the questionnaires, and an independent researcher re-scored 16 (53%) of the questionnaires. The Cohen's Kappa was .62 indicating substantial agreement between the two independent coders. Any discrepancies were discussed, and agreed scores were allocated. Parents with multiple sclerosis were also asked about the duration of their condition and the type of multiple sclerosis.

Parental anxiety and depression scores were assessed with the Hospital Anxiety and Depression Scale (15). Hospital Anxiety and Depression Scale is a reliable and valid instrument for assessing anxiety and depression scores in medical patients (16), and the general population (17).

Parental expressed emotion towards adolescents was measured using the Five Minute Speech Sample (18). Instructions to the parent are: "I'd like to hear your thoughts about your child. Tell me what kind of a person he/she is, and how you get along together". The interviewer remains silent, and the parent speaks without interruption for 5 minutes. The Five Minutes Speech Sample scores range from 0-5 (19), with higher scores indicating higher criticism. A total score of 5 indicates: negative initial statement (1), negative relationship (1), low warmth (1), presence of critical comments (1), and

absence of positive comments (1). The total expressed emotion scores, as well as the counts of positive and negative comments subscales, were used in the analysis. The first author of the children adaptation of the Five Minute Speech Sample (20), coded 10 out of 68 speech samples (14%) to determine inter-rater reliability. Inter-rater reliability was Kappa=1 indicating almost perfect agreement between the two independent coders based on Landis & Koch (21) criteria. There were some minor differences in four of the 10 Five Minutes Speech Sample, but these differences did not change the overall scoring.

Adolescents completed the Strength and Difficulties Questionnaire (22). This scale has good validity and internal reliability (23). The Strength and Difficulties Questionnaire includes 25 items divided into five scales of five items each: Hyperactivity, Emotional Difficulties, Conduct Problems, Peer Problems and Prosocial Behaviour. In order to ensure a comprehensive description of psychological adjustment, we examined the broad constructs of internalising and externalising problems, as suggested by the authors of the scale (24). We combined the Emotional and Peer Problems subscales into an internalising subscale and the Behavioural and Hyperactivity subscales into an externalising subscale.

Analyses were performed using SPSS 20 statistical package. To assess the presence and degree of relationships between parent and child variables and the two adjustment outcomes, we performed Pearson's correlations (or t-tests or ANOVA for the categorical data). Hierarchical linear modelling analysis was used to test whether significant correlations identified in the bivariate analysis

remained significant when building an adjustment model. Hierarchical linear modelling appropriately addresses the hierarchically nested design of the data, in which lower level units, adolescents (level 1), were nested within a higher nested unit, families (level 2) (25).

We conducted four separate hierarchical linear models with adolescent internalising problems at baseline and follow-up and adolescent externalising problems at baseline and follow-up as dependent variables. Due to the large number of preliminary analyses conducted we considered $p < 0.01$ as the level of significance. Significant variables ($p < 0.01$) identified in the preliminary bivariate analysis were entered in each model.

Results

Seventy-five adolescents, 56 parents with multiple sclerosis and 40 partners without multiple sclerosis from 58 families, took part. Ten families were single parent families. Two partners could not take part due to illness severity, three parents without multiple sclerosis did not want to take part and did not give any reason, one partner was too busy to take part and one, according to his partner, did not want to talk about multiple sclerosis.

Parents with multiple sclerosis were between 34 to 60 years old (mean: 45.96, $SD=5.52$) and the majority were mothers ($n=46$, 82%). Illness severity varied from 3.5 to 7.5 on the Expanded Disability Status Scale and the majority ($n=35$, 62.5%) had relapsing-remitting multiple sclerosis. Half of the parents with multiple sclerosis ($n=28$) were unemployed due to their illness. Partners were between 36 and 60 years old (mean=47.2, $SD=5.2$). Five

partners (12.5%) were unemployed due to their partner's multiple sclerosis, and 27 partners (67.5%) had reduced working hours as a result of their partner's condition. Table 1 summarises the clinical variables of the sample at baseline and follow-up. Parents' with MS and adolescents' variables remained stable over the six months. Partners' without MS anxiety ($t=2.32$, $df=41$, $p<0.05$) and depression ($t=2.04$, $df=41$, $p<0.05$) scores reduced at follow-up.

Insert Table 1 here

The total score of the Five Minutes Speech Sample of the parent with multiple sclerosis was positively skewed and was transformed using log transformation. The scale appeared normal after the transformation. Only a small percentage of parents with multiple sclerosis ($n=16$, 23.5%) and partners without multiple sclerosis ($n=12$, 28.6%) scored high on expressed emotion (a score of 2 or above) towards their adolescent children. This proportion is similar to the figures of high expressed emotion reported in the literature for mothers without chronic physical conditions and their children that range from 13%-29.6% (26-29), and significant lower when compared with the figures reported for parents with a chronic mental health condition, e.g. 69% of high expressed criticism for mothers with depression (30). When we compared anxiety, depression and illness severity scores, between parents with high (scores 2 or above), and low expressed emotion (scores lower than 2), we found no statistical significant differences.

To ascertain whether multiple sclerosis related cognitive impairment might affect or confound results on the expressed emotion, we explored the relationship between the cerebral subscale of the Expanded Disability Status

Scale and the Five Minute Speech Sample scores. The correlation between the cerebral subscale (cognitive items) and the Five Minute Speech Sample for the parent with multiple sclerosis was not statistically significant ($r=-.094$), indicating that cognitive ability did not influence participant responding.

Table 2 shows that baseline parental and adolescents' demographic characteristics were unrelated to adolescents' internalising and externalising problems at baseline and follow-up. One exception was the age of partners without multiple sclerosis. In other words, the younger the age of the partners, the greater adolescents' internalising problems. To explore this correlation further, we split partners into two groups, younger ($n=34$) versus older ($n=21$) based on the median of the age range. Further analysis showed that younger partners were more likely to have reduced their working hours ($n=19$; 56%) compared to the older group ($n=8$, 38%). Also, a larger percentage of the older group had completed a University degree ($n= 11$, 52%), compared to the younger group ($n=4$, 12%). There were no significant differences between the two age groups in anxiety, depression or expressed emotion scores. Since the age of the parent without multiple sclerosis was related to adjustment outcome, we entered this variable in the hierarchical linear modelling analysis.

Illness characteristics were unrelated to adolescents' adjustment outcome at baseline and follow-up. However, anxiety, depression and expressed emotion of parents with multiple sclerosis were associated with adolescents' internalising and externalising symptoms at baseline and follow-up.

Insert Table 2 here

Hierarchical Linear Modelling Analysis

Baseline family and individual factors associated with adolescents' internalising and externalising symptoms at baseline and follow-up ($p < .01$) were included in the hierarchical models (Table 3). The age of the partners without multiple sclerosis ($\gamma_{\text{age}} = -0.31$, $p = .001$) was the most significant predictor of baseline internalising problems, with adolescents of younger parents reporting more internalising symptoms. Baseline depression scores of the parents with multiple sclerosis correlated with adolescents' internalising symptoms at follow-up ($\gamma_{\text{dep}} = 0.31$, $p = .004$). Expressed emotion score of the parents with multiple sclerosis ($\gamma_{\text{EE}} = 4.35$, $p = .052$) were associated with increased adolescents' externalising symptoms at follow-up.

Insert Table 3 here

Discussion

Depression symptoms and expressed emotion in parents with multiple sclerosis, rather than the severity and type of multiple sclerosis had an impact on adolescents' internalising and externalising symptoms at both baseline and follow-up. Adolescent adjustment remained stable over time suggesting that those who had problems at baseline continued to do so six months later.

Previous studies have shown multiple sclerosis severity to contribute to offspring psychosocial difficulties (2, 3, 5). The focus on adolescence might explain this difference as previous work included a wider age range. Illness characteristics may have the most impact on younger children who need more help with daily tasks such as dressing and preparing meals. The way we

measured illness severity may also play a role. For example, Pakenham and Burnsnall (3) measured multiple sclerosis severity and impairment based on offspring reports and found an association with poorer adjustment in children. Maybe the perception of illness severity in children and adolescents has a greater influence on adjustment compared with parental reported measures of illness severity.

Similar to other studies of parental multiple sclerosis (4-6), more depression symptoms in parents with multiple sclerosis were associated with adolescent adjustment. This study extended previous research to highlight the role of parental anxiety for adolescents' psychological difficulties. Interestingly, there was no association between anxiety or depression symptoms in parents without multiple sclerosis and their children. In this study, the majority of the parents with multiple sclerosis were mothers, and previous research has found that maternal (versus paternal) emotional distress most strongly impacts children's psychological difficulties (31-33). The question remains as to whether emotional distress of the parent with multiple sclerosis, rather than the partner without multiple sclerosis, is more important or whether the fact that the majority of the parents with multiple sclerosis were also mothers biased this finding.

Research has found parental expressed emotion associated with symptoms of psychopathology in offspring (19, 34, 35). Similarly, high expressed emotion of parents with multiple sclerosis at baseline was related to externalising symptoms (i.e. hyperactivity and conduct problems) for adolescents at baseline and six months later suggesting effects are sustained

over time. Parents who received a high score on the scale describing a negative relationship with their children showed low warmth and were more likely to start the speech sample with a negative statement about their child. Parents' critical comments also included criticism on adolescents' behaviours like untidiness, not wanting to spend time in the house and being moody; in other words, characteristics that can be attributed to this developmental stage. However, it should be noted that only a minority of the current sample showed high criticism.

The age of the partner without multiple sclerosis was associated with adolescents' baseline internalising problems. In particular, the younger the parent without multiple sclerosis (mostly fathers), the more adolescents' reported internalising problems. A meta-analysis showed that the younger age of an ill parent is associated with more problems for children and that younger families are typically characterised by low socioeconomic status (1). The authors of the meta-analysis argued that young families may have fewer financial and educational resources to deal with the impact of the long-term condition (1). Similarly, we found that younger partners differed from the older group in terms of reduced working hours and education.

Limitations of this study need to be noted. Although the Strengths and Difficulties Questionnaire is a well-validated and widely used measure of adolescent adjustments it does not detect difficulties in areas such as school performance, relationships with siblings, somatic symptoms or impact on adolescents' plans for the future. Additionally, collapsing of adolescents' psychological variables into internalising and externalising symptoms reduced

the number of analytical comparisons but it can also obscure independent variance between the original four adjustment variables. Also, parental anxiety, depression, expressed emotion are not specifically related to multiple sclerosis. Further research needs to compare families with a parent with multiple sclerosis with families with a parent with other long-term illnesses to elucidate whether the pattern of results found in this study are related to multiple sclerosis or whether they characterise families with a parent with a long-term physical or mental illness. Additionally, the reverse direction of the associations reported here might be possible. Expressed emotion, anxiety and depression symptoms of the parents with multiple sclerosis could be influenced by child adjustment. The current study design and sample size could not explore the complex and circular interrelationships between the reported variables.

In summary, our study highlighted how the increased anxiety and depression symptoms of parents with multiple sclerosis affect offspring's psychological adjustment. Also, findings showed that illness characteristics, such as illness severity, type and duration were not directly linked with adolescents' adjustment. Interventions for distress in multiple sclerosis may benefit from including a family focused approach. Further, for the first time, parental expressed emotion was explored in the context of parental long-term physical illness and showed that parental criticism is associated with adolescents' externalising problems both cross-sectionally and longitudinally. On the other hand, parental positive comments played a protective role for internalising and externalising problems. Psychological interventions for families may focus

on supporting the relationships and interactions between parents and children. For example, a systemic family therapy perspective could address the circular relationship between parental communication style and child distress and simultaneously focus on both.

Clinical messages:

- Parental multiple sclerosis severity, type and duration are not associated with offspring psychological adjustment.
- Anxiety and depression symptoms of parents with multiple sclerosis are associated with offspring psychological adjustment.
- Parental expressed criticism was associated with increased adolescent externalising symptoms.

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Competing interest

None declared.

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Table 1

Comparisons for parental and adolescents' variables between baseline and six-month follow-up

	Baseline means(SD)	Follow-up means (SD)	Correlations	T test(df)
Parents with MS				
N	56	48		
Illness severity	5.64 (1.12)	5.53 (1.14)	.83***	1.12(54)
Anxiety	7.47 (5.32)	7.70 (4.9)	.84***	-.62(59)
Depression	6.42 (5.05)	6.47 (5.34)	.90***	-.16(59)
Parent without MS				
N	40	33		
Anxiety	7.60 (4.63)	6.69 (5.17)	.87***	2.32(41)*
Depression	4.98 (3.91)	4.38 (4.58)	.91***	2.04(41)*
Adolescents				
N	75	62		
Internalising problems	5.52 (3.49)	5.34 (4.10)	.75**	.09(61)
Externalising problems	6.65 (3.95)	6.10 (4.06)	.77**	1.42 (61)

*p<.05, **p<.01, ***p<.001

Table 2

Relationships between baseline (T1) parental anxiety and depression scores, MS factors, demographics and expressed emotion variables and baseline (T1) and six-month follow-up (T2) adjustment scores (SDQ)

	Internalising problems T1 SDQ ¹ (n=75)	Internalising problems T2 SDQ (n=62)	Externalising problems T1 SDQ (n=75)	Externalising problems T2 SDQ (n=62)
<i>MS factors</i>				
Time since diagnosis	r=0.019	r=0.068	r=-0.116	r=-0.053
Illness severity (EDSS)	r=0.093	r=0.088	r=0.201	r=0.175
Type of MS	F(2,65) = 0.208	F(2,53) = 1.012	F(2,65) = 0.736	F(2,53) = 0.656
Current relapse	t(66) = -0.613	t(54) = -0.602	t(66) = 1.005	t(54) = 1.246
<i>Demographic factors</i>				
Gender-parent with MS	t(71) = -0.749, p=0.457	t(59) = -0.465, p=0.644	t(71) = -0.735, p=0.465	t(59) = -0.44, p=0.656
Gender-parent without MS	t(53) = 0.817, p= 0.418	t(43) = 0.742, p=0.462	t(41) = 1.309, p= 0.198	t(43) = 0.645, p=0.522
Gender-adolescent	t(69) = 2.384, p=0.020	t(60) = 1.610, p=0.113	t(73) = -1.194, p=0.236	t(60) = -0.307, p=0.760
Age-parent with MS	r=-0.183	r=-0.041	r=-0.007	r=0.094
Age-parent without MS	r=-0.399**	r=-0.321*	r=-0.341*	r=-0.188
Age-adolescent	r=-0.060	r=-0.048	r=-0.067	r=-0.236
Single vs 2-parent family	t (66) = -0.613, p=0.542	t(54) = -0.602, p=0.550	t(66) = 1.005, p=0.319	t(54) = 1.246, p=0.218
<i>Parent with MS</i>				
Expressed Emotions (FMSS ²)	r=0.044	r=-0.186	r=0.380**	r=0.341**
Critical Comments (FMSS)	r=0.095	r=-0.142	r=0.302*	r=0.276*
Positive Comments (FMSS)	r=-0.117	r=-0.040	r=-0.195	r=-0.295*
Depression (HADS ³)	r=0.415**	r=0.386**	r=0.348**	r=0.352**
Anxiety (HADS)	r=0.369**	r=0.246	r=0.495**	r=0.484**
<i>Parent without MS</i>				
Expressed Emotion (FMSS)	r=-0.084	r=-0.157	r=0.142	r=0.059
Positive Comments (FMSS)	r=-0.125	r=-0.086	r=-0.308*	r=-0.286
Critical Comments (FMSS)	r=-0.032	r=-0.234	r=0.236	r=0.309
Anxiety (HADS)	r=0.174	r=0.166	r=0.129	r=0.281
Depression (HADS)	r=0.222	r=0.050	r=0.136	r=0.226

* $p < .05$, ** $p < .01$, 1.SDQ=Strength and Difficulties Scale, 2.FMSS=Five Minutes Speech Sample, 3.HADS=Hospital Anxiety and Depression Scale

Table 3

Hierarchical regression models between baseline (T1) parental anxiety and depression scores and expressed emotion and adolescents' adjustment at baseline (T1) and follow-up (T2)

	Internalising problems T1 SDQ¹ (n=75)	Internalising problems T2 SDQ (n=62)	Externalising problems T1 SDQ (n=75)	Externalising problems T2 SDQ (n=62)
Intercept (SE, df)	18.26 (4.05,44.28)***	3.29 (0.81, 33.40)***	2.56 (0.80, 64)**	2.94 (1.02, 29.29)**
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<i>Parent without multiple sclerosis</i>				
Age	-0.31(0.08,44.80)***			
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<i>Parent with multiple sclerosis</i>				
Depression (HADS ²)	0.16(0.11,29.45)	0.32 (0.10, 30.40)**	-0.03 (0.11, 64)	0.06 (0.15, 26.24)
Anxiety (HADS)	0.07(0.10,29.45)		0.34 (0.11, 64)**	0.25 (0.14, 25.15)
Expressed Emotion (FMSS ³)			6.66 (1.91, 64)**	5.35 (2.19, 52.38)*

* $p < .05$, ** $p < .01$, *** $p < .001$

1.SDQ=Strength and Difficulties Scale, 2.HADS=Hospital Anxiety and Depression Scale, 3 .FMSS=Five Minutes Speech Sample