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Original Citation

Brooks, Joanna, Daghish, Julie and Wearden, Alison (2013) Attributions, distress and behavioural responses in the significant others of people with Chronic Fatigue Syndrome. *Journal of Health Psychology*, 18 (10). pp. 1288-1295. ISSN 1359-1053

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Attributions, distress and behavioural responses in the significant others of people with Chronic Fatigue Syndrome

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Abstract

To test an attribution-emotion model of reactions to chronic fatigue syndrome (CFS/ME), 30 significant others of 30 adult patients with CFS/ME were administered a semi-structured interview about their beliefs regarding the patient's illness, and completed questionnaire measures of distress and behavioural responses to the patient. Spontaneous causal explanations (attributions) for illness events, symptom exacerbation and negative patient mood were extracted and coded. Significant other distress and negative behavioural responses towards the CFS/ME patient were associated with attributing illness events to causes personal and internal to the patient. Our findings may inform future family-based interventions for CFS/ME.

Keywords

Chronic fatigue syndrome, attributions, family members; distress; behavioural response

Chronic Fatigue Syndrome (also known as myalgic encephalomyelitis or ME; CFS/ME) is a debilitating condition with a primary symptom of severe and persistent fatigue, often resulting in substantial functional impairment (e.g. Fukuda et al., 1994, Cairns & Hotopf, 2005; Collin et al., 2011; Jason et al., 2011). With symptoms which may be difficult to describe to outsiders and with no clear aetiology, CFS/ME is a complex and controversial condition (Guise, McVittie & McKinlay, 2010). The ways in which those close to patients (their 'significant others') respond to CFS/ME may have important implications for the patient's own management of their condition and associated illness outcomes, such as psychological adjustment and symptom experience (Romano et al., 2009; White et al., 2006). The present study examines factors which may determine how significant others respond, both emotionally and behaviourally, to patients with CFS/ME, focusing on causal attributions as a potential precursor of significant other responses.

Attribution theory suggests that causal explanations (attributions) made by an observer for negative events concerning another, influence the observer's affective response to the event and thus their behavioural reaction (e.g. Weiner, 1985). Attributional analyses of reactions to physical and mental health conditions suggest that the framework can be useful in understanding why and how people respond as they do to illness in others (e.g. Dijker & Koomen, 2003; Weiner, 1993; Weiner, Perry & Magnusson, 1988).

Attributional statements offering a causal explanation for a negative event can

be extracted from spontaneous speech or interview data and coded using one of several attributional coding systems. The Leeds Attributional Coding System (LACS; e.g. Munton et al., 1999) codes spontaneously uttered attributional statements with respect to the speakers' beliefs about causality along the following attributional dimensions. Each cause is coded as being (1) either internal or external to the actor (internal/external); (2) controllable or uncontrollable by the actor (controllable/uncontrollable); (3) chronic or transient (stable/unstable); (4) something which causes only the event in question or which may also cause other events (specific/global); and (5) as personal or idiosyncratic to the actor, or a cause which would be expected to be observed more universally (personal/universal). The LACS has been successfully used to examine relatives' attributions in a variety of different illness conditions (e.g. Wearden et al., 2006; Barrowclough et al., 2008; Tarrier et al., 2002).

A small number of studies have examined attributions of significant others of CFS/ME patients, although none using the LACS. White and colleagues (2006) examined causal attributions about illness onset in CFS/ME patients and their close others. Close others' causal attributions explaining illness onset in terms of factors internal to the patient were associated with more unhelpful support attempts by close others and with greater depression and anxiety amongst patients. Research in primarily mental health conditions suggests that when significant others attribute aspects of illness to factors internal and personal to the patient and controllable by the patient, they hold the patient more responsible, are more critical of the patient (Barrowclough & Hooley, 2003) and

are more distressed (Arefjord et al., 2002). While White et al. (2006) examined causal attributions for illness onset, to date there has been no research on significant others' causal attributions for symptom exacerbations and ongoing illness events in CFS/ME.

The aims of this study were to examine how causal attributions made by significant others of CFS/ME patients for the ongoing symptoms of CFS/ME (rather than its onset) might be associated with significant others' levels of distress and their behavioural responses to the patient. Studies of significant others' responses to CFS/ME to date (e.g. Romano et al., 2009; Schmalting et al., 2000) have employed measures derived from the chronic pain literature. In the present study we used an empirically-derived measure of self-reported responses specifically developed for use with relatives of CFS/ME patients (the Family Response Questionnaire [FRQ]; Cordingley et al., 2001). In line with previous literature, we hypothesised that significant others who attributed illness events to factors that were controllable by, internal to, and personal to the patient would report more negative responses towards the patient, operationalised as higher scores on the rejecting –hostile scale of the FRQ, and would also be more distressed. Secondly, we hypothesised that these relationships would hold when patient illness severity was controlled for.

Method

Participants

30 CFS/ME patients who fulfilled the Centre for Disease Control (CDC) criteria

for CFS (Fukuda et al., 1994) were recruited from two hospital CFS/ME clinics in the North West of England and asked to nominate their closest adult family member (their 'significant other') to participate with them in the study. Ethical approval was obtained from the relevant NHS ethics committee. All participants gave written informed consent for participation.

Measures

Interview with significant others

A shortened and adapted version of the Camberwell Family Interview (Leff & Vaughn, 1985) allowed the emergence of spontaneous attributions while talking about the patient's illness. It covered the following topics:

- (a) Household composition, relationship between patient and respondent
- (b) Symptom onset and diagnosis
- (c) Illness history
- (d) Illness status over past year/ past three months
- (e) Current symptoms
- (f) Patient's management of the illness; involvement of family members in care
- (g) Illness course and predictability (remittance and relapse); expectations for future
- (h) Impact of condition on patient and significant other's daily life

Significant other questionnaires

The General Health Questionnaire (GHQ-28; Goldberg & Williams, 1988) was used as a measure of psychological distress. The GHQ consists of four

subscales (somatic symptoms, anxiety and insomnia, social dysfunction and severe depression). For this study, items were scored using a Likert format (0-3) and summed. Higher scores indicate greater distress.

The 25- item FRQ (Cordingley et al., 2001) was used to assess behavioural responses to the CFS/ME patient. Respondents indicated the extent to which they agreed with statements describing their responses to the patient. The questionnaire produces scores on four subscales labelled by the authors as: sympathetic, active-engagement, rejecting/ hostile, and concern with self. In our sample, we found that two items “insisted that X rest” and “reminded X to slow down” originally assigned to the scale labelled “sympathetic responses” correlated with each other ($r=.556$, $p=.001$), but not with other scale items. We therefore summed these items separately and labelled them “encouragement to rest”.

To control for the possible confounding effect of relationship quality, significant others completed a visual analogue scale measure (0 - extremely unhappy to 6 - perfectly happy) of their overall relationship happiness.

Patient measures

Given that differentiating between symptoms of CFS/ME and symptoms of depression is known to be potentially problematic, Brown, Kaplan & Jason (2011) suggest using measures developed specifically for use with medical populations to measure depression amongst CFS/ME patients. In this study,

patient-completed questionnaire measures of physical functioning (SF-36 physical functioning scale; Ware & Sherbourne, 1992) fatigue (Chalder fatigue scale, Likert scored; Chalder et al., 1993) anxiety and depression (Hospital Anxiety and Depression Scales; Zigmond & Snaith, 1983) were used to control for level of patient's illness severity.

Procedure

One week prior to the agreed interview date, questionnaire measures were sent out to participants. Significant others were interviewed individually and confidentially in their own homes by the first author. Interviews were audio-recorded and transcribed in full.

Extraction, coding and scoring of attributions

Unprompted attributional statements containing a clearly expressed cause of events in the following categories were extracted for coding:

- (a) Illness events (including illness episodes, all possible symptoms)
- (b) Negative changes in symptoms (including exacerbation, relapse, new symptoms)
- (c) Patient's negative mood/ emotional state

To obtain reliability for extractions, attributions were extracted independently from 6 transcripts by AW and JB. Of 97 attributions extracted, 85 (88%) were in common. Statements were then extracted and coded from remaining transcripts by JB. Using a procedure similar to that described previously (e.g. Wearden et

al., 2006), for each dimension, a dichotomous rating was assigned (internal, controllable, personal, stable and global dimensional poles were coded as 1; external, uncontrollable, universal, unstable and specific poles were coded as 3). To obtain reliability for codings, JB and JD separately coded 50 extracted attributions. Unweighted Cohen's kappas were as follows: internal/ external, $k=0.96$ (98% agreement); controllable/ uncontrollable, $k=0.96$ (98%), personal/ universal, $k=0.79$ (90%); stable/ unstable, $k=0.88$ (94%); global/ specific, $k=0.85$ (92%).

To calculate proportional attribution scores on each dimension, the number of attributions coded 1 were divided by the total number of attributions extracted. Scores therefore varied between 0 and 1, with a higher score indicating a greater proportion of attribution statements rated 1 (e.g. a higher score on the internal/ external dimension indicates the respondent made proportionally more attributions internal to the patient). This calculation procedure is described in the LACS (Munton et al., 1999) and elsewhere (e.g. Wearden et al. 2006).

Analysis

Data distributions were examined for normality. Pearson's correlations were used to examine relationships between pairs of variables. First, to determine potential confounding variables, correlations between patient physical functioning, fatigue, anxiety, depression, significant other's relationship happiness, and significant others' distress and behavioural responses were examined. To test our hypotheses, correlations were computed between

participants' proportional attribution scores and distress and behavioural responses, controlling for significant confounders where appropriate. For hypothesised correlations a significance level of $p < .05$ was accepted.

Results

Description of sample

The age of the patient sample ranged from 16 to 62 years, with a mean of 41 years. 73.3% ($n = 22$) were female. Mean (SD) scores on patient measures were: physical functioning score 42.7 (SD 23.1); fatigue 27.9 (SD 4.5); anxiety 9.2 (4.8); depression 8.3 (4.3). The age of the significant other sample ranged from 21 to 71 years, with a mean of 48 years. 60% ($n = 18$) were female. Mean (SD) significant other relationship happiness score was 4.2 (1.7). 60% ($n = 18$) of the significant others were the patient's spouse, 6.7% ($n = 3$) were the patient's child, 33.3% ($n = 10$) were the patient's parent. All but two patients (28; 93.3%) lived with their significant others.

Attributions

A total of 452 attributional statements were extracted and coded. The mean number of attributional statements per interview was 15.07 (SD=7.46; range 2-32). Summary statistics for proportional attribution scores for each attributional dimension were as follows: internal 0.488 (SD 0.15); controllable 0.385 (SD 0.22); personal 0.314 (SD 0.19); stable 0.471 (SD 0.19); global 0.522 (SD 0.24).

Preliminary analyses

There were significant correlations between significant other encouragement to rest and patient fatigue ($r=.387$, $p=.034$) and physical functioning ($r=-.457$, $p=.013$). Physical functioning was also correlated with significant other active engagement ($r=-.493$, $p=.007$). The correlation between patient depression and significant other distress approached significance ($r=.354$, $p=.055$). Significant others' relationship happiness was correlated with concern for self ($r= -.387$, $p=.038$), and with distress ($r=-.562$, $p=.002$). All other correlations in the preliminary analysis were non-significant.

Significant others' mean (SD) GHQ and FRQ scale scores are given in Table 1.

Table 1. Summary statistics and Pearson's correlations (*p-values*) between distress (GHQ), FRQ scale scores and proportional attribution scores

	Mean (SD)	Internal	Controllable	Personal	Stable	Global
GHQ total	24.43 (11.21)	.362 .049	.075 .629	.550 .002	.283 .130	.138 .466
FRQ Symp	2.64 (0.76)	.050 .794	-.017 .927	.087 .683	.029 .878	.080 .674
FRQ Active	2.54 (0.79)	.146 .441	.064 .737	.248 .186	-.100 .598	-.047 .805
FRQ Reject	0.53 (0.58)	.433 .017	.157 .407	.418 .021	.097 .609	-.124 .514
FRQ Self	1.37 (0.92)	.237 .208	.026 .892	.418 .021	.185 .329	.144 .447
FRQ Rest	2.87 (0.96)	-.076 .691	-.383 .036	.014 .942	.083 .661	.326 .079

Attributions and significant other behavioural responses

Proportional attribution scores on the internal and personal dimensions, but not the controllability dimension were moderately positively correlated with rejecting-hostile responses (Table 1). As none of the illness severity variables were correlated with the rejecting-hostile response style, no further analyses were carried out here.

Unexpectedly, controllability attributions were associated with encouragement to rest (Table 1). This correlation was repeated using partial correlations to control for fatigue severity and physical functioning. The correlation was reduced to $pr = -.371$, $p=.053$ when physical functioning was controlled for and to $pr = -.319$, $p=.098$ when fatigue was controlled for.

Attributions and significant other distress

Proportional attribution scores on the internal dimension were moderately correlated with distress. The correlation was repeated controlling for patient depression ($pr = .422$, $p=.022$) and significant other's relationship happiness ($pr = .319$, $p = .098$). Proportional attribution scores on the personal dimension were strongly correlated with distress. This correlation was repeated controlling for patient depression ($pr = .524$, $p=.002$) and significant other relationship happiness ($pr = .443$, $p=.018$).

Discussion

In line with our first hypothesis, rejecting- hostile responses from significant others were associated with their making attributions for negative illness events to factors internal and personal to the patient. We had also predicted that attributing illness events to causes controllable by the patient would be associated with rejecting hostile responses. This was not found to be the case. Similarly, in accordance with our second hypothesis, internal and personal attributions were also associated with greater distress amongst significant others, while controllability attributions did not correlate with distress. The

pattern of findings was not altered when patient illness severity variables were controlled for, although some correlations became marginally non-significant in this small sample.

Taken together these findings suggest that it is the attribution of negative illness events to factors idiosyncratic to the patient, which may drive distress and negative responses in CFS/ME. It may be that attributing ongoing illness events to factors internal and personal to the CFS/ME patient is a source of distress to significant others because such factors may be perceived as less amenable to change. While it was not hypothesised, the correlation between controllability attributions and encouragement to rest is interesting. This suggests that significant others saw exacerbations in symptoms as due to the patient doing too much – a belief which might have been expected to engender solicitous rather than negative responses.

While preliminary and requiring replication, the present study may have important implications, as there is emerging evidence that significant others' responses to CFS/ME may impact on patients' fatigue and disability. Using a measure adapted from the chronic pain literature (Kerns et al., 1985), Schmaling, Smith and Buchwald (2000) asked CFS/ME patients about their partners' responses to their condition. Patients reporting that their partners were solicitous had higher levels of fatigue and disability, particularly in the context of a satisfactory relationship. More recently, Romano and colleagues (2009) found that solicitous significant other responses were associated with

increased patient activity limitation, while negative significant other responses – more akin to the rejecting-hostile responses studied here - were associated with higher levels of patient distress. Potentially, the solicitous responses in Schmalting et al.'s (2000) and Romano et al.'s (2009) studies were similar to the “encouragement to rest” response style in our study. Recent treatment studies (Wearden et al., 2010; White et al., 2011) suggest that in order for patients to improve, there needs to be an element of gradually increasing activity. Therefore an encouragement to activity limitation, even if entirely well-intentioned and driven by the significant other's belief that avoiding activity can control the illness, may be associated with worse outcomes for the patient.

Our study was informed by attribution-emotion theory (Weiner, 1985; Weiner 1993). The interpretation of our findings is based on a model of CFS/ME which regards disrupted activity patterns, driven by patients, and possibly by significant others', illness beliefs, as a maintaining factor. Other authors have used a framework in which significant others have rated their own attempts at support, and have reported that making internal attributions for the cause of CFS/ME was associated with unhelpful support attempts (such as distraction).

The generalisability of our findings may be limited by the cross-sectional design of the study, the modest size and the characteristics of the sample, which was recruited entirely from a hospital setting. We did not have data on comorbidities or illness chronicity, nor on wider aspects of the family setting, and other research has suggested that there are specific partner variables which may be

associated with worse physical functioning in CFS/ME (Johnson et al., 2010). Three patients referred into the project declined to participate because of their poor health, and two patients did not participate because their significant other was unwilling to do so. It is therefore possible that our sample was less unwell and relationship functioning more favourable than in the CFS/ME population as a whole. Indeed scores on the rejecting –hostile FRQ subscale were lower than for other response types.

We accepted an alpha level of $p=.05$ for tests of hypothesised relationships; unhypothesised findings should be treated with caution until replicated. Nevertheless, this is the first study to examine significant others' attributions using an established attributional coding system. It suggests a potential pathway from significant others' attributional beliefs (which may be amenable to change) to patient functioning and distress, with the significant others' responses and distress as the mediating factors. This pathway should be investigated in future studies examining all three sets of variables, preferably longitudinally.

Copies of the interview schedule and the manual detailing rules for the extraction and coding of attributions are available from the first author on request.

Acknowledgements

The authors thank all those who participated in the research for their co-operation and for their time.

This work was supported by a PhD studentship awarded to the first author by the Economic and Social Research Council (grant number R42200134160).

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