

FOCUS ON RESEARCH

TESTING A THEORY – ILLNESS REPRESENTATIONS AND COPING

A study to examine the relationship between illness representations, coping and psychological adjustment in sufferers of chronic fatigue syndrome (Moss-Morris *et al.* 1996).

This study examined the interrelationship between illness representations, coping and psychological adjustment in the context of chronic fatigue syndrome (CFS). The aim of the study was to test directly elements of Leventhal's self-regulatory model and to examine whether the way an individual makes sense of their illness (their illness representation) and the way they cope with their illness (their coping strategies) relates to their level of functioning (the outcome measure).

Background

Chronic fatigue syndrome (sometimes called myalgic encephalomyelitis (ME) or post-viral fatigue syndrome) has interested psychologists for over a decade as it appears to have no apparent simple organic origin or to be a psychiatric disorder. Recent theorists have suggested that CFS is best characterized as an interaction between psychological and physical factors with cognitive and behavioural responses mediating between an acute organic illness and a chronic syndrome. Because of the hypothesized role of cognitions in the maintenance/progression of CFS, Moss-Morris *et al.* aimed to examine the role of illness cognitions and coping strategies in sufferers' level of functioning.

Methodology

Subjects 520 members of the Australian and New Zealand Myalgic Encephalomyelitis Society were sent an invitation to take part in the study, of whom 308 returned the

consent forms and were sent a questionnaire. A total of 233 CFS sufferers (189 female and 44 male) completed and returned the questionnaire and were included in the data analysis. These subjects ranged in age from 18 to 81, 61 per cent were married, 55 per cent had received tertiary education and the mean length of illness was 10.8 years.

Design The study involved a cross-sectional design with all subjects completing a questionnaire once.

Measures Subjects were sent a questionnaire consisting of the following measures:

1 *The Illness Perception Questionnaire*. This questionnaire measured illness representations and included items reflecting the following aspects of illness representations:

- *Identity*: This consisted of a set of 12 core symptoms (e.g. pain) and 13 symptoms specific to CFS (e.g. tiredness). Subjects were asked to rate each symptom according to how often they experienced them from 'never' to 'all the time'.
- *Time line*: This consisted of items relating to the subjects' predicted length of their illness (e.g. 'My CFS will last a long time').
- *Control/cure*: This consisted of items relating to the degree to which the subjects believed that their illness could be controlled/cured (e.g. 'There is a lot I can do to control my symptoms').
- *Consequences*: Subjects were asked to rate statements concerning the perceptions of the possible consequences (e.g. 'My illness has strongly affected the way I see myself as a person').
- *Cause*: subjects also rated statements relating to the cause of their illness (e.g. 'Stress was a major factor in causing my illness').

2 *Coping strategies*. Subjects completed a shortened version of the COPE Inventory (Carver *et al.* 1989), which has been designed to measure aspects of coping. The authors included items relating to *problem-focused* coping (e.g. active coping, planning, suppression of competing activities, seeking support for instrumental reasons), *emotion-focused* coping (e.g. positive reinterpretation and growth, venting emotions, seeking emotional support), *behavioural disengagement* coping (e.g. using substances for distraction) and *mental disengagement* coping (e.g. wishful thinking).

3 *Level of functioning*: Subjects completed the five-item mental health scale (MHI5) as a measure of psychological adjustment, a four-item vitality scale (Ware and Sherbourne 1992) as a measure of subjective well-being and the Sickness Impact

Profile (Bergner *et al.* 1981) as a measure of dysfunction.

Results

The relationship between components of illness representations

The results showed that a strong illness identity was related to a belief in serious consequences and a more chronic time line (e.g. 'I have lots of symptoms, my illness has serious effects on my life and I believe that it will last for a long time'). A chronic time line was related to more negative beliefs about consequences and a belief that the illness was less controllable and less curable (e.g. 'I believe that my illness will last for a long time, that it has a serious effect on my life and that it cannot be either controlled or cured'). In addition, a belief that CFS was caused by psychological factors (e.g. stress) was related to a greater belief in serious consequences (e.g. 'My illness was caused by stress and has serious effects on my life').

The relationship between illness representations and coping

The results showed a positive relationship between identity (the illness representation) and coping strategies such as planning venting emotions, behavioural disengagement and mental disengagement (e.g. 'I experience lots of symptoms and cope by forming plans of action, venting my feelings, and distracting myself from my symptoms by using substances such as alcohol and by engaging in wishful thinking'). The results also showed a positive relationship between consequences (the illness representation) and coping strategies such as planning, suppression of competing activities, seeking emotional social support, venting emotions, mental disengagement (e.g. 'I believe that my illness has seriously effected my life, and cope by forming plans of action, stopping doing other activities, talking to my friends about my feelings, expressing my emotions and thinking about other things'). In addition, the results showed a positive relationship between internal control/cure (the illness representation) and coping strategies such as active coping, planning, positive reinterpretation and a negative relationship with behavioural disengagement (e.g. 'I believe that I can control/cure my illness and cope actively, form plans, attempt to see my illness in a positive light and do not use substances'). Finally, the results showed a belief that the illness would last a long time (the illness representation) was related to coping by suppressing competing activities,

behavioural disengagement (e.g. 'I believe that my illness is chronic and cope by not doing other activities and using substances') and a belief that the illness was caused by psychological factors was related to behavioural disengagement (e.g. 'I believe that stress caused my illness and cope by drinking alcohol').

The relationship between illness representations and level of functioning

The results showed that the illness representation components of illness identity, emotional causes of the illness, controllability/curability and consequences had the strongest overall association with measures of functioning, suggesting that individuals who had the most symptoms, believed that their illness was out of their control, caused by stress and had serious consequences, showed low levels of psychological adjustment and well-being and higher levels of dysfunction.

The relationship between coping and levels of functioning

The results from this analysis showed that psychological dysfunction and low psychological well-being were related to behavioural and mental disengagement and that psychological adjustment was related to positive reinterpretation, seeking emotional support, not using substances and not venting emotions.

Conclusion

The results from this study provide support for the predicted association between cognitive variables (illness representations and coping) and level of functioning (psychological adjustment, well-being and dysfunction) in CFS. In addition, the results provide support for Leventhal's self-regulatory model as illness representations were related to coping and a measure of outcome (level of functioning). However, because of the cross-sectional nature of the design it is not possible to say whether illness representations cause changes in either coping or outcome and as the authors conclude 'only a prospective design can clarify some of these issues'.