Illness representations in young people with Chronic Fatigue Syndrome

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(Received 20 July 2005; in final form 21 April 2006)

Abstract
Leventhal’s commonsense model of self-regulation has attracted a great deal of research in recent years, but its possible implications for understanding young people with chronic illness have received little attention. The purpose of this study is to examine children and young people with chronic fatigue syndrome (CFS) and to explore (a) the characteristics of their illness representations, (b) whether those representations are associated with their physical functioning and perceived quality of life and (c) whether coping strategies may act as mediators between representations and those outcomes. A total of 85 participants, ranging in age from 8 to 25 years, were recruited from the website of a self-help group for young people with CFS. They were asked to complete three questionnaires, measuring illness representations, coping strategies, and physical functioning and quality of life. The results showed that illness representations formed characteristic patterns, that they were associated with both physical functioning and quality of life, and that coping partially mediated the relationship between illness representations and outcome. We conclude that young people’s representations of their CFS play an important role in coping and outcome. The implications of the findings are discussed for both theory and clinical practice, and suggestions are made for further research.

Keywords: Illness representations, young people, chronic fatigue syndrome

Introduction
Chronic fatigue syndrome (CFS) is a disease of uncertain aetiology, defined by persistent or relapsing unexplained tiredness. According to the most widely used diagnostic criteria, set out by the Centers for Disease Control and Prevention in 1994 (Fukada et al., 1994; Prins & van der Meer, 2006), fatigue must have lasted for at least 6 months, with a new or definite onset not brought on by organic

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ISSN 0887-0446 print/ISSN 1476-8321 online/06/000001–16 © 2006 Taylor & Francis
DOI: 10.1080/14768320600774595
disease or continuing exertion. There must be evidence that the fatigue is not alleviated by rest, and that it results in a substantial reduction in previous occupational, educational, social and personal activities. In addition, four or more of the following symptoms must have been present concurrently for 6 months or longer: impaired memory or concentration, sore throat, tender cervical or axillary lymph nodes, muscle pain, pain in several joints, new headaches, un-refreshing sleep or malaise after exertion. Diagnosis of the disorder is based on symptoms reported by the patient and can be made only after alternative medical or psychiatric causes have been excluded. Prevalence estimates in USA are between 0.25 and 0.45% (Jason et al., 1999; Reyes et al., 2003) and, in UK, they are perhaps as high as 0.5% (Wessely, Chalder, Hirsch, Wallace, & Wright, 1997). The disorder is difficult to diagnose (Carruthers et al., 2003; Wessely, Hotopf, & Sharpe, 1998), has a poor prognosis (Cairns & Hotopf, 2005) and often fails to respond to treatment (Price & Couper, 2000; Reid, Chalder, Cleare, Hotopf, & Wessely, 2000; Whiting et al., 2001).

This study is focused on children and young people. Prevalence is lower than in adults (Chalder, Goodman, Wessely, Hotopf, & Meltzer, 2003; Jones, Nisenbaum, Solomon, Reyes, & Reeves, 2004; Jordan et al., 1998), but the disorder can be very damaging because of its effects on the young person’s education, physical activities and social development. Little research on this age group has been published so far, however (Prins & van der Meer, 2006), and our study will try to redress the balance. The purpose of the article is to use Leventhal’s self-regulatory model (Leventhal, Meyer, & Nerenz, 1980) to examine the illness representations of young people with CFS, their relationship with functioning and quality of life and the possible mediating role of coping strategies.

**Leventhal’s self-regulatory model**

At the heart of Leventhal’s model lies the notion that we reflect on our lives and form subjective perceptions and interpretations of our experiences, called representations. In the case of illness, patients cluster their ideas around five central themes that provide a framework for making sense of their symptoms and for directing action and coping (Buick, 1997). The five are the label placed on the disease by the patient and the symptoms associated with it (identity); the individual’s ideas about how one gets the disease (cause); the perceived physical, social, financial and emotional effects of the disease (consequences); expectations about the duration and course of the disease (timeline); and patients’ ideas about what they themselves, or their medical carers, can do to promote recovery or manage symptoms (cure/controllability). Leventhal’s model proposes an explicit causal link between illness representations and behaviour: representations guide coping (Weinman & Petrie, 1997) which, in turn, influence health outcomes (such as physical and psychological adjustment). The self-regulatory model is thus a mediation model, in which coping is seen as mediating the influences of illness representations on health outcomes (Hagger & Orbell, 2003).
The most widely used quantitative measure of illness representation is the Illness Perception Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris, & Horne, 1996), which was developed to assess all five components. In the updated version, the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002), the ‘controllability’ and ‘timeline’ subscales of the original have both been separated into two factors: ‘personal’ and ‘treatment control’ for controllability, and ‘acute/chronic’ and ‘cyclical’ for timeline. The IPQ-R also takes into consideration two additional factors not included in the original questionnaire (Hagger & Orbell, 2005): emotional representations, which are thought to run parallel to cognitive representations (Leventhal, Meyer, & Nerenz, 1980); and ‘illness coherence’, a meta-cognition of the patient’s perceived utility of his or her illness representation.

Applying the self-regulatory model in CFS

There is a considerable amount of literature on the role of representations in coping and outcome in adult chronic illness (Hagger & Orbell, 2003; Kaptein et al., 2003; Scharloo & Kaptein, 1997; Schiaffino & Cea, 1995; Schiaffino, Shawaryn, & Blum, 1998). Examples of disorders examined include irritable bowel syndrome (Rutter, C. L. & Rutter, D. R., 2002), chronic obstructive pulmonary disease (Scharloo et al., 1998; Scharloo, Kaptein, Weinman, Willems, & Rooijmans, 2000), asthma (Jessop & Rutter, 2003), epilepsy (Kemp, Morley, & Anderson, 1999), diabetes (Griva, Meyers, Newman, 2000; Hampson, 1997), rheumatoid arthritis (Groarke, Curtis, Coughlan, & Gsel, 2005), psoriasis (Fortune, Richards, Griffiths, & Main, 2002; Fortune, Richards, Main, & Griffiths, 2000; Scharloo et al., 1998) and many others (Hagger & Orbell, 2003). Though there is preliminary evidence that the concept of illness representations can be usefully applied to children as well as adults (Goldman, Whitney-Saltiel, Granger, & Rodin, 1991; Paterson, Moss-Morris, & Butler, 1999), no study, to our knowledge, has examined the approach in children with existing chronic illness.

As to CFS, a number of studies using Leventhal’s self-regulatory model have been published in the last few years, and several consistent features have been identified. In particular, high scores on the identity, consequences and timeline scales have suggested that CFS patients typically believe that their illness has a wide range of symptoms, has a great impact on their lives and is likely to last for a long time (Moss-Morris, 1997; Moss-Morris, Petrie, & Weinman, 1996; Moss-Morris et al., 2002; Petrie, Moss-Morris, & Weinman, 1995). The pattern has not always been replicated in studies with other physical illnesses, however, indicating that the representation of CFS is more than just a facet of having any chronic physical illness. When compared with populations with rheumatoid arthritis, chronic back pain, or diabetes, CFS patients have been found to have significantly higher scores for illness identity and consequences, and are more likely than other groups to attribute their condition to a virus or pollution, but less likely to attribute it to their own behaviour (Moss-Morris et al., 1996). Not only are the
illness representations distinct in CFS, but research has demonstrated that they are also remarkably stable over time. For example, Moss-Morris (1997) reported that 6-month test–retest correlations were all greater than 0.70 for illness identity, controllability and consequences, and greater than 0.50 for timeline.

While the self-regulatory model proposes that illness representations will direct coping strategies, which in turn will influence adaptive outcomes such as disability and quality of life, Moss-Morris and Wrapson (2003) suggest that, in the case of CFS, illness representations may play an even greater role. Cross-sectional, longitudinal and prospective studies alike have indicated that they are influential in both the onset of the condition and the maintenance of the disability and symptoms experienced (Chalder & Williams, 1998; Heijmans, 1998; Moss-Morris & Petrie, 2001). Miles and Shevlin (2003) conclude that two separate pathways may exist – from illness representations to coping and from there to disability. People with CFS who hold what Moss-Morris and Wrapson (2003) term ‘negative beliefs’ about the identity, consequences and timeline of their illness tend to withdraw passively from its management. Those who are more positive, however, and attribute their symptoms to externally caused physical disease, often perceive rest to be a particularly effective way of coping. This leads them to limit their activity to what they can manage and hence gives them a greater sense of control over the illness and helps them to adjust.

Other research has focused on the distinction between emotion-focused and problem-focused coping (Carayon, 1993). Moss-Morris et al. (1996), for example, found that patients who had a strong illness identity and believed their disorder to be outside their control, reported more serious consequences, and used more passive, emotion-focused coping strategies. Conversely, those who believed that they had more control over their illness, and foresaw consequences that were less serious, used more active, problem-focused coping strategies. The combination of a representation of CFS as serious and uncontrollable with a passive emotion-focused coping strategy was associated with higher levels of physical disability and lower levels of psychological well-being.

The present study

Almost all the research outlined in the previous section has been with adults. Whether any of the findings will be supported in children and young people with CFS is unknown, and it is that question that provides the focus for our work. The purpose of the study is to explore the nature of illness representations among young people with CFS and to examine the relationships among representations, coping and outcome. As in most of the works outlined above, outcomes are measured by self-reported daily functioning and quality of life. It is hypothesised that illness representations will form an identifiable pattern, that they will be associated with coping strategies and health outcome and that, following Leventhal et al. (1980), the link will be mediated by coping strategy.
Method

Participants and procedure
Participants were 85 members of a support group for young people with CFS, who replied to an advertisement for volunteers on the message board of the group’s website. There were 5 males and 80 females, ranging in age from 8 to 25 years (mean 18 years 7 months, SD = 3.3). The frequencies were one aged 8, one aged 11, 22 aged 14–16, 26 aged 17–19, and 35 aged 20–25. The mean duration of the disorder was 59 months (SD = 37.4; range 9–168). The advertisement invited people to contact the first author, via email, telephone or post, if they were interested in participating in a short, questionnaire-based study on the way young people cope with CFS. Individuals who made contact were sent a pack through the post, including a copy of the questionnaire, a consent form, and an accompanying information sheet giving details about the procedure, confidentiality and purpose of the study. Participants were asked to sign the consent form to indicate that they had understood the information sheet and agreed to take part in the study. Participants under the age of 16 were asked to gain permission from a parent/carer, who was also required to sign the consent form. Questionnaires returned without a signed consent form were excluded from the study. To protect anonymity and confidentiality, participants were instructed not to place their name or address anywhere on the questionnaire, but instead to devise a code, consisting of their initials and day and month of birth, and write it on the front sheet of the questionnaire. The code ensured that participants could withdraw their data from the study at any time – though none did. Finally, participants were asked to complete the questionnaire and return it in the pre-paid envelope we supplied, along with the signed consent form. The procedures were approved by the authors’ departmental ethics committee and the support group’s management team.

Materials
The questionnaire measured illness representations, coping strategies and outcome. For each scale, Cronbach’s alphas were calculated and totals were computed.

Illness representation. Illness representations were measured by the IPQ-R, a self-report questionnaire with seven scales (Moss-Morris et al., 2002). The seven scales include “identity” (the number of symptoms identified as part of the disorder – 14 items), “timeline” (the expected course of the disorder – acute/chronic or cyclical – 10 items), “consequences” (how the illness would affect the patient’s life – 6 items), “control-cure” (the extent to which the illness would be controllable by the patient or the treatment – 11 items), “causes” (the patient’s attributions as to what had led to or precipitated the illness – psychological factors, risk factors, immune problems or accident/chance – 18 items), “emotional representations” (how the patient responded to the illness emotionally – 6 items), and “illness coherence” (how structured and rounded a view the patient had of the
disorder – 5 items). For identity, respondents answered ‘yes/no’ for the presence of each symptom; for the other dimensions, there were five-point scales, from ‘strongly disagree’ to ‘strongly agree’.

Coping. Coping was measured by the Illness Management Questionnaire (IMQ) (Carayon, 1993), a 45-item questionnaire that asked participants to rate which coping strategies they had employed during the last 6 months, on six-point scales from ‘never’ to ‘always’. The measure was designed to assess illness-focused coping in people with CFS, and consists of four subscales: maintaining activity, accommodating to the illness, focusing on symptoms and information-seeking.

Outcome. Outcome was assessed by two measures. The first was the Quality of Life Scale (QOLS) (Chibnall & Tait, 1990). Participants were asked to rate the extent to which their life was satisfying, in each of seven areas of daily living: social life, family life, hobbies and recreation, educational and intellectual development, daily routine, romantic experiences, and expectations and hopes for the future. They rated each area on a seven-point scale, from ‘totally unsatisfying’ to ‘completely satisfying’. The second measure was the Functional Ability Scale (FAS) (Moss, 1995). This asked the participants to rate the extent to which their symptoms affected their ability to perform everyday activities of living, from 0 ‘no symptoms even following physical or mental activity’ to 100% ‘severe continuous symptoms’.

Results

Illness representations

Descriptive data and Cronbach’s alphas are given in Table I. Four representations subscales produced alphas below 0.6 and were dropped from further consideration: consequences, personal control, cause (immunity), and cause (accident/chance). Scores for illness identity ranged from 5 to 14, with a mean of 9.84 symptoms (SD = 2.12). The three symptoms most frequently endorsed were fatigue (97.6% of respondents), loss of strength (96.5%) and sleep difficulties (94.1%). Possible scores for the two timeline subscales ranged from 1 to 5, with high scores indicating a strong belief that CFS is a chronic or cyclical condition. The means were 2.58 (SD = 0.58) for acute/chronic and 3.46 (SD = 0.79) for cyclical, indicating that respondents saw their illness as predominantly cyclical or fluctuating. For treatment control, possible scores ranged from 1 to 5, with high scores indicating a strong belief that CFS can be controlled by treatment, and the mean was 2.99 (SD = 0.69). The next two subscales were concerned with causes, with high scores denoting a strong belief that the factor played an important role in the aetiology of CFS. For the ‘psychological attributions’ subscale, the mean was just below the mid-point, 2.47 (SD = 0.80), and for risk factors it was well below 1.80 (SD = 0.51), indicating that risk factors were generally seen to play little part. Participants were also asked to indicate in free response form what they
did perceive to be the main causes of their CFS. From the total of 36 causes that patients noted, the top four were virus (33% of all causes given), stress or worry (13%), overwork (10%) and altered immunity (10%). For ‘illness coherence’, the possible range of scores was 1 (low) to 5 (high), and the mean was 2.88 (SD = 0.90), close to the mid-point. For ‘emotional representations’, scores ranged from 1.40 (low) to 5 (high), and the mean was 3.29 (SD = 0.72), indicating a generally strong emotional response to the illness.

**Relationships among illness representations**

Relationships among illness representations were analysed by Pearson’s r (top section of Table II). To guard against type I error, alpha was set at \( p < 0.01 \). Participants who reported more symptoms (a strong illness identity) also reported less confidence that treatment would control their condition, and treatment control in turn correlated negatively with chronic timeline, indicating that those who believed their condition was chronic had less faith in treatment as a means of controlling it. Attributing CFS to psychological causes was associated with a strong belief in risk as a causal factor too.

**Relationships between illness representations and coping**

Relationships between illness representations and coping strategies were similarly examined by Pearson’s r (middle section of Table II), and alpha was again set

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**Table I. Descriptive statistics.**

<table>
<thead>
<tr>
<th>Illness representation subscale</th>
<th>Mean</th>
<th>SD</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Illness identity</strong></td>
<td>9.84</td>
<td>2.12</td>
<td>0.61</td>
</tr>
<tr>
<td><strong>Timeline: Acute/chronic</strong></td>
<td>2.58</td>
<td>0.57</td>
<td>0.64</td>
</tr>
<tr>
<td><strong>Timeline: cyclical</strong></td>
<td>3.46</td>
<td>0.79</td>
<td>0.65</td>
</tr>
<tr>
<td><strong>Consequences</strong></td>
<td>3.62</td>
<td>0.44</td>
<td>0.50</td>
</tr>
<tr>
<td><strong>Personal control</strong></td>
<td>2.69</td>
<td>0.40</td>
<td>0.19</td>
</tr>
<tr>
<td><strong>Treatment control</strong></td>
<td>2.99</td>
<td>0.69</td>
<td>0.71</td>
</tr>
<tr>
<td><strong>Illness coherence</strong></td>
<td>2.88</td>
<td>0.90</td>
<td>0.90</td>
</tr>
<tr>
<td><strong>Emotional representations</strong></td>
<td>3.29</td>
<td>0.72</td>
<td>0.75</td>
</tr>
<tr>
<td><strong>Cause: Psychological attributions</strong></td>
<td>2.46</td>
<td>0.80</td>
<td>0.77</td>
</tr>
<tr>
<td><strong>Cause: Risk factors</strong></td>
<td>1.80</td>
<td>0.51</td>
<td>0.60</td>
</tr>
<tr>
<td><strong>Cause: Immunity</strong></td>
<td>3.39</td>
<td>0.69</td>
<td>0.23</td>
</tr>
<tr>
<td><strong>Cause: Accident/chance</strong></td>
<td>2.28</td>
<td>0.87</td>
<td>0.04</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Coping subscale</th>
<th>Mean</th>
<th>SD</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Maintaining activity</strong></td>
<td>3.19</td>
<td>0.96</td>
<td>0.92</td>
</tr>
<tr>
<td><strong>Accommodating to the illness</strong></td>
<td>3.76</td>
<td>0.94</td>
<td>0.87</td>
</tr>
<tr>
<td><strong>Focusing on symptoms</strong></td>
<td>3.15</td>
<td>0.96</td>
<td>0.83</td>
</tr>
<tr>
<td><strong>Information-seeking</strong></td>
<td>3.49</td>
<td>1.08</td>
<td>0.85</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Mean</th>
<th>SD</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical functioning</strong></td>
<td>54.63</td>
<td>22.22</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Quality of life</strong></td>
<td>3.54</td>
<td>1.06</td>
<td>0.73</td>
</tr>
</tbody>
</table>
Table II. Correlations (Pearson's r) of illness representations, coping strategies and outcomes.

<table>
<thead>
<tr>
<th>Identity</th>
<th>Timeline: Acute/chronic</th>
<th>Timeline: Cyclical</th>
<th>Treatment control</th>
<th>Illness coherence</th>
<th>Emotional representations</th>
<th>Cause: Psychological attributions</th>
<th>Cause: Risk factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Timeline: Acute/chronic</td>
<td>0.09</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Timeline: Cyclical</td>
<td>–0.18</td>
<td>0.17</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Treatment control</td>
<td>–0.28***</td>
<td>–0.29***</td>
<td>–0.17</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Illness coherence</td>
<td>0.08</td>
<td>0.14</td>
<td>0.17</td>
<td>–0.15</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Emotional representations</td>
<td>0.09</td>
<td>0.06</td>
<td>–0.18</td>
<td>–0.18</td>
<td>0.10</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Cause: Psychological attributions</td>
<td>–0.17</td>
<td>–0.09</td>
<td>0.11</td>
<td>–0.01</td>
<td>–0.11</td>
<td>0.20</td>
<td>–</td>
</tr>
<tr>
<td>Cause: Risk factors</td>
<td>–0.05</td>
<td>–0.11</td>
<td>0.04</td>
<td>–0.01</td>
<td>0.22</td>
<td>0.03</td>
<td>0.53***</td>
</tr>
<tr>
<td>Activity</td>
<td>–0.09</td>
<td>0.09</td>
<td>0.09</td>
<td>0.03</td>
<td>0.14</td>
<td>–0.12</td>
<td>0.03</td>
</tr>
<tr>
<td>Accommodation</td>
<td>0.09</td>
<td>–0.27</td>
<td>–0.15</td>
<td>0.03</td>
<td>–0.17</td>
<td>–0.15</td>
<td>0.11</td>
</tr>
<tr>
<td>Focusing on symptoms</td>
<td>0.15</td>
<td>0.20</td>
<td>0.26</td>
<td>–0.38***</td>
<td>0.30**</td>
<td>0.49***</td>
<td>0.16</td>
</tr>
<tr>
<td>Information seeking</td>
<td>0.01</td>
<td>–0.16</td>
<td>0.04</td>
<td>0.20</td>
<td>–0.01</td>
<td>0.14</td>
<td>0.00</td>
</tr>
<tr>
<td>Physical functioning</td>
<td>–0.31***</td>
<td>0.14</td>
<td>0.16</td>
<td>0.06</td>
<td>–0.24</td>
<td>–0.08</td>
<td>0.22</td>
</tr>
<tr>
<td>Quality of life</td>
<td>–0.27***</td>
<td>–0.12</td>
<td>0.00</td>
<td>0.28***</td>
<td>–0.17</td>
<td>–0.34***</td>
<td>0.00</td>
</tr>
</tbody>
</table>

**p < 0.01.

***p < 0.001.
at $p < 0.01$. Just one coping strategy produced statistically significant relationships: focusing on symptoms was associated with weak perceived treatment control, strong illness coherence and high levels of emotional representations. That is, people who dwelt on their symptoms as a way of coping were uncertain that treatment would control their illness, had an ill-formed picture of it, and responded to it with strong emotions.

**Relationship between illness representations and outcome**

Relationships between illness representations and outcome were again examined by Pearson’s $r$ (bottom section of Table II), and alpha was set once more at $p < 0.01$. Participants who reported the best functioning reported the lowest illness identity – that is, the least symptoms. Those who reported good quality of life said they had fewer symptoms but greater faith in treatment, and they responded less emotionally.

**Relationships among illness representations, coping and outcome**

The relationships among illness representations, coping strategies and the two outcomes were tested by regression-based path analysis. Representation components were allowed to influence outcome directly, as were all the coping strategies, but also indirectly, through coping strategies. Analyses were conducted iteratively, with statistically non-significant pathways dropped after each round, until only paths that reached significance remained.

The first analysis examined physical functioning (Figure 1), and the model accounted for 21% of the variance. Illness identity and illness coherence had two direct effects: people who reported fewer symptoms and a less coherent picture of their illness reported better functioning. The relationship between believing in risk factors as causal and physical functioning was mediated by coping through maintaining activity: people who believed that their illness was caused by risk factors were more likely to remain active, which in turn resulted in better perceived functioning.

The second analysis examined perceived quality of life (Figure 2), and this time the model accounted for 40% of the variance. Illness identity again had a direct effect: people who reported fewer symptoms reported better quality of life. The relationship between chronic timeline and quality of life was mediated by coping through accommodating to the illness: the more people saw their condition as acute, the more they accommodated to it, which in turn had a positive effect on quality of life. Accommodating to the illness can include opting out of difficult and stressful aspects of one’s life, and it may perhaps be this that accounts for the better quality of life. The paths to quality of life from illness coherence, emotional representations and treatment control were all mediated by coping through focusing on symptoms: the more coherent the perception of the illness, the stronger the emotional representation and the weaker the faith in treatment the stronger is the focus on symptoms. Focusing on symptoms, in turn, was associated with poorer quality of life.
Figure 1. Path analysis for physical functioning.
Notes: *p < 0.05, **p < 0.01.
Adjusted $R^2 = 0.21$, $df = 3$, $75$, $F = 7.96$, $p < 0.001$.

Figure 2. Path analysis for quality of life.
Notes: *p < 0.05, **p < 0.01, ***p < 0.001.
Adjusted $R^2 = 0.42$, $df = 4$, $77$, $F = 15.93$, $p < 0.001$. 
Discussion

Our findings show that (a) children and young people have identifiable representations of their CFS, and that (b) those representations are linked to both coping strategies and outcome. (c) Moreover, in accordance with Leventhal’s model, coping strategies sometimes act as mediators between illness representations and outcome.

Characteristics of young people’s representations of their CFS

Respondents attributed a wide range of symptoms to their CFS, held a coherent view of its possible causes, perceived that it has a serious and negative impact on their lives, and often believed that it is caused by a virus – all of which is consistent with the evidence from adults with CFS (Moss-Morris, 1997; Moss-Morris, Petrie, & Weinman, 1996; Moss-Morris et al., 2002; Petrie, Moss-Morris, & Weinman, 1995). The new measures included in the IPQ-R revealed that respondents perceived the symptoms and pattern of their illness as more cyclical than chronic (the opposite of what has generally been found in adults with CFS), and also developed strong emotional representations. It is conceivable that the representations of young women differ from those of young men, but we were unable to explore sex differences in our data since more than 90% of respondents were female – against an estimated 75% or so in most studies of adults (Cairns & Hotopf, 2005) – perhaps because of our method of recruitment.

Links between illness representations and coping and outcome

Our findings indicate a pattern of associations that is no less subtle and complex than that of adults. As in studies of adults, respondents who perceived the timeline of their CFS as acute were more likely to accommodate to the illness (Moss-Morris, 1997). Moreover, those who had strong emotional responses to their illness and little faith in treatment often used strategies of focusing on their symptoms (Carayon, 1993) which, in turn, led to disengagement from daily activities (Heijmans, 1998; Moss-Morris, 1997; Moss-Morris & Petrie, 2000; Moss-Morris et al., 1996). Good daily functioning was found to be associated with having a clear picture of the condition, believing that one had few symptoms and seeing psychological factors as causes. This contradicts the evidence from studies of adults that specific causal attributions, and the ratio of physical to psychological attributions, are unrelated to disability (Heijmans, 1998; Moss-Morris, 1997; Moss-Morris et al., 1996). Like physical functioning, quality of life was also associated with having few symptoms, but beliefs in the efficacy of treatment were associated with better reported quality of life, this time confirming the evidence from adults (Heijmans, 1998; Moss-Morris, Petrie, & Weinman, 1996). Conversely, a belief in risk factors as causal and a strong emotional response to the illness were both related to a poorer quality of life. The finding for emotional representations is particularly important because a similar pattern is beginning to emerge for chronic illness in adults too (Jessop & Rutter, 2003; Jessop, Rutter, Sharma, & Albery, 2004), now that a measure of emotional
representations has been included in the IPQ-R and interest in emotion has been revived.

The mediating role of coping

For both functioning and quality of life, we found good evidence of direct links between representations and outcome. Consistent with Leventhal’s suggestion, however, for quality of life we also found evidence of mediation by coping – through maintaining activity for physical functioning, and through accommodation to the illness, information seeking and focusing on symptoms. Among adults, C. L. Rutter & D. R. Rutter (2002) also found evidence of mediation, in their study of irritable bowel syndrome, but mediation appears to be the exception in adult chronic illness (Heijmans, 1998; Kemp, Morley, & Anderson, 1999; Scharloo, Kaptein, Weinman, Willems, & Rooijmans, 2000). It is interesting to speculate that outcome for children and young people may perhaps be more influenced by the way they cope than is the case for adults – consistent with the more common view among younger people that their CFS is cyclical rather than chronic – but much more evidence is needed before a proper conclusion can be drawn.

Clinical implications

Two main findings of particular importance for clinical practice have emerged from our study. The first is that both accommodating to the illness and keeping active are adaptive strategies for good outcomes: accommodating to the illness for quality of life and maintaining activity for physical functioning. These two coping strategies have sometimes been seen as in opposition (Carayon, 1993), with advocates of the cognitive-behavioural model of CFS emphasising the importance of maintaining activity (Chalder & Williams, 1998; Surawy, Hackman, Hawton, & Sharpe, 1995; Wessely, 1996) but patient groups promoting the use of pacing and other strategies involving accommodation (Gantz & Holmes, 1989; Ho-Yen, 1990). Our own findings suggest that the strategies are not at odds, but rather reflect the differing goals of patients and clinicians in managing the illness. For children and young people, a subjective feeling of well-being is more important than the ability to perform tasks; for clinicians, outcome is better assessed more ‘objectively’, through physical activity.

The second finding for clinical practice is that focusing on symptoms is associated with poor physical functioning. Cause and effect cannot be disentangled, since our design was cross-sectional and not longitudinal. However, a causal relationship would suggest that a cognitive behavioural approach to treatment may be beneficial for patients – moving the focus away from symptoms, by reducing the strength of emotional representations, encouraging a more diffuse view of CFS, and strengthening belief in treatment. Cognitive behaviour therapy has emerged from systematic reviews as the one successful treatment for patients with CFS (Price & Couper, 2000; Reid, Chalder, Cleare, Hotopf, & Wessely, 2000; Whiting et al., 2001), including
young people (Chalder, Tong, & Deary, 2002); and, in two randomised controlled trials, improvement has been shown to be present even several years after the start of treatment (Deale, Husain, Chalder, & Wessely, 2001; Powell, Bentall, Nye, & Edwards, 2004). Both effectiveness and acceptability to patients who are seriously ill, however, remain under-researched (Department of Health, 2002). According to the Medical Research Council’s report on CFS (Medical Research Council, 2002), patients who are severely affected are likely to need the most help in improving their quality of life, which means that other forms of intervention should be explored too. The self-regulation model provides clinicians with just such an opportunity (Cameron, Petrie, Ellis, Buick, & Weinman, 2005; Moss-Morris, Sharon, Tobin, & Baldi, 2005; Petrie, Broadbent, & Meechan, 2003).

**Future research**

Our study has been one of few to investigate systematically the illness representations of young people with a chronic illness, and we believe that there are several implications for future research. First, further work is needed with young people, and with other disorders that they may develop, to determine whether our findings are unique to CFS or general to chronic disorders. Second, emotional representations and illness coherence deserve much greater attention, something that has been made feasible by the development of the IPQ-R. Third, researchers must develop additional *objective* measures of outcome – behavioural measures, for example, and indices of immune dysfunction – since error and bias are hard to overcome in subjective ratings. Fourth, further attention is needed to the continuing problem highlighted by our finding that clinicians and patients may have quite different perspectives and goals for managing the illness. Finally, there is an urgent need for the prospective, longitudinal studies that are essential for determining the direction of causality that cross-sectional research cannot. Such studies would also make possible a proper examination of the dynamic nature of Leventhal’s approach, in which reappraisals feed back continuously into the patient’s model and change its structure. This may well be of critical importance to understanding CFS and chronic illness in general – in both adults and young people – but as yet it has been all but ignored.

**References**


Illness representations in young people with CFS


