THE ILLNESS PERCEPTION QUESTIONNAIRE:
A NEW METHOD FOR ASSESSING THE
COGNITIVE REPRESENTATION OF ILLNESS

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The Illness Perception Questionnaire (IPQ) is a new method for assessing cognitive representations of illness. The IPQ is a theoretically derived measure comprising five scales that provides information about the five components that have been found to underlie the cognitive representation of illness. The five scales assess identity - the symptoms the patient associates with the illness, cause - personal ideas about aetiology, time-line - the perceived duration of the illness, consequences - expected effects and outcome and cure control - how one controls or recovers from the illness. The IPQ has a specific number of core items but allows the user to add items for particular patient groups or health threats. Data is presented supporting the reliability and validity of the IPQ scales in different chronic illness populations.

Keywords: Illness perceptions; questionnaire; reliability; validity; chronic illness; personal models.

INTRODUCTION

The onset of illness gives rise to a range of problems, which can vary greatly from patient to patient, even in those with the same condition. In recent years health psychologists have shown that, in order to make sense of and respond to these problems, patients create their own models or representations of their illness. The most influential theoretical framework adopted in this work is the self-regulation model of Leventhal and colleagues, who have proposed that patients' illness representations are based around distinct components which, in turn, determine coping (Leventhal, Nerenz and Steele, 1984; Leventhal and Diefenbach, 1991). Thus they maintain that each patient will have their own ideas about the identity, cause, time-line, and consequences of their illness. Lau and colleagues (1989) have indicated that patients' models also incorporate beliefs about the cure and controllability of the condition. Recent overviews of research in this area, based on differing methodologies across a range of different clinical conditions, confirm the consistency and validity of these five components of patients' illness representations (Skelton and Croyle, 1991).

The identity component is concerned with patients' ideas about the label, the nature of their condition (i.e. associated symptoms) and the links between these. The causal component comprises the patient's ideas about the likely cause or causes of the illness and the time-line component indicates their perceptions of the likely duration of their health conditions.
problems and these have been categorised as acute/short-lasting, chronic, or cyclical/episodic. The \textit{consequences component} reflects the individual's beliefs about the illness severity and likely impact on physical, social and psychological functioning. The \textit{cure component} indicates the extent to which the patient believes their condition is amenable to cure or control. Although the components of illness representations are distinct in the sense they can have specific effects on coping and outcomes, they are not necessarily independent. Thus there may be very direct links between the identity and consequences components or between representations of the cause and control of an illness. These representations come into play as soon as patients experience their initial symptoms and typically change with disease progression, emergent symptoms and treatment responses. Leventhal proposes that these representations reflect the patient's cognitive response to symptoms and illness, and that emotional responses are processed in parallel to illness representations (Leventhal \textit{et al.}, 1984).

Although there is increasing interest in this area of work, different methodologies have been employed by researchers (Leventhal and Nerenz, 1985). In their original work, Leventhal and colleagues used in-depth, semi-structured interviews focusing on patients' concrete illness experiences in order to elicit their representations. While this approach was clearly productive, it is time-consuming, produces large variations in the quantity and quality of response, and no psychometric data have been produced in support of this methodology. In one of their studies investigating a community sample's cognitions about six different illnesses, they have used a questionnaire to assess illness representations (Prohaska, Leventhal, Leventhal and Keller, 1985) and other researchers have developed questionnaires for this purpose (Lacroix, 1991), but these have not generally been theoretically derived and have not been evaluated with more than one type of patient group. Moreover, one of these measures (Turk, Rudy and Salovey, 1986) appeared to provide data which was inconsistent with the selfregulation model, but this was based on the ratings of contrasting diseases by patient, student, and nursing samples rather than on patients' representations of their own illness. Also, Lau \textit{et al.} (1989) were critical of the way in which these data were analysed and concluded that the findings were quite compatible with illness representation theory.

In view of the growing interest in patients' representations of illness, both in attempting to understanding the nature of illness-related coping and for developing interventions to facilitate self management in chronic illness, we feel that there is scope for developing an assessment questionnaire which is theoretically-based and psychometrically sound, but with sufficient flexibility for the user to add items which are particularly salient for specific patient groups or in relation to specific health threats or contexts. In this paper we describe the structure and development of a new instrument, the \textit{Illness Perception Questionnaire (IPQ)}, which contains five scales that assess the components of illness representations.

\textbf{METHOD}

\textit{Development of the Illness Perception Questionnaire (IPQ)}

The test items were theoretically-derived to assess each of the five illness representation components. The symptom list incorporated twelve common symptoms from other symptom checklists (eg. Bowling, 1991). The rest of the items were either generated by patients or by us to fit with Leventhal's description of illness representation components (Leventhal and Nerenz, 1985). The patient-generated items were elicited during preliminary interviews and the items which were selected were those which reflected specific representations. These items and those initially generated by us were assessed for comprehensibility in early pilot studies and a few additional changes were made to ensure that each item could be understood clearly.

The full IPQ with instructions to subjects is shown in Appendix (1). The \textit{Identity} scale is comprised of 12 core symptom items that the patient is asked to rate for frequency on a four point scale ranging from “all of the time” to “never” according to how often each symptom is experienced as part of the patient's illness. This core list of items may be added to by researchers to tailor the scale to specific illnesses and lists for some illnesses are already in use including an expanded 28 item \textit{Identity} scale for CFS which includes such items as “muscle pain”, “light sensitivity” and “mild fever” (see Moss-Morris, Petrie and Weinman, in press). The \textit{Identity} scale is scored by summing the number of items endorsed at “occasionally” or greater, so that the total score ranges from 0 to 12 for the core list. This therefore provides a simple measure of the number of symptoms perceived to be associated with the illness. Since the alternative, weighted scoring system is highly correlated with this, we chose the simpler method.

The items from the four other IPQ scales are presented in a mixed order and rated by the patient on a five point scale ranging from “Strongly Disagree” to “Strongly Agree” (scored 1 to 5). After reverse scoring appropriate items, scores for \textit{Time-line}, \textit{Consequences} and \textit{Cure Control} scales are obtained by summing all the scales items and dividing by the number of items. For the \textit{Cause} scale it is not appropriate to sum all of the items as each item represents a specific causal belief, although some researchers may find it appropriate to combine items for their needs (e.g. external vs internal causal factors).

In the most general version of the IPQ, each items refers to “Illness” but it also possible to replace this with the name of a particular illness (e.g. diabetes, asthma etc.) in studies with selected illness populations. Copies of the general and specific versions are available from the authors. A significant other/carer version of the IPQ has also been developed.
to elicit the partner's/carer's cognitive model of the patient's illness. This version may be appropriate where researchers want to assess the illness perceptions of significant others, caretakers or other family members. Further details about this scale are available from the authors.

Data assessing the reliability and validity of the scales, are shown below. One additional stage of checking the items comprised a comparison of the questionnaire with a semi-structured interview designed to elicit illness representations, using the guidelines offered by Leventhal and Nerenz (1985). This study was conducted with a sample of 52 insulin-dependent diabetic patients and it found that all the themes mentioned in the interview were also evident in the questionnaire data. Moreover, the questionnaire appeared to provide a more complete data set since about a third of the interview respondents failed to provide information about some or all of the illness representations components. Some aspects of this interview - questionnaire comparison study are also discussed in the final section of this paper.

PARTICIPANTS

Data from 7 illness groups provide the basis for evaluating the psychometric properties of the IPQ scales. The diabetes and rheumatoid arthritis populations were recruited from a London teaching hospital out-patient facility. The renal patients were all undergoing renal dialysis and the asthma patients had all been in-patients at the same London hospital. Chronic fatigue syndrome (CFS) patients were contacted through a New Zealand national support group on the basis that they reported a confirmed medical diagnosis of CFS. Chronic pain patients were recruited from a private Auckland pain clinic where they were seeing an anaesthetist pain specialist. The myocardial infarction (MI) patients were involved in a large prospective study of recovery from first-time MI in Auckland. The demographic and other characteristics of these samples are presented in Table (1).

Table 1 Characteristics of illness samples used in the IPQ studies

<table>
<thead>
<tr>
<th></th>
<th>Hospitalized MI Patients</th>
<th>Discharged MI Patients</th>
<th>Discharged MI Patients</th>
<th>Chronic Fatigue Syndrome</th>
<th>Rheumatoid Arthritis</th>
<th>Diabetes</th>
<th>Pain</th>
<th>Renal</th>
<th>Asthma</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>143</td>
<td>104</td>
<td>91</td>
<td>115</td>
<td>22</td>
<td>88</td>
<td>60</td>
<td>32</td>
<td>193</td>
</tr>
<tr>
<td>Sex (% Female)</td>
<td>1%F</td>
<td>13%F</td>
<td>12%F</td>
<td>73%F</td>
<td>81%F</td>
<td>48%F</td>
<td>40%F</td>
<td>41%F</td>
<td>66%F</td>
</tr>
<tr>
<td>Age (Mean, SD)</td>
<td>53.0 (8.5)</td>
<td>53.8 (8.2)</td>
<td>53.5 (8.1)</td>
<td>48.2 (1.26)</td>
<td>62.2 (16.6)</td>
<td>45.6 (15.9)</td>
<td>42.2 (13.9)</td>
<td>48.3 (15.6)</td>
<td>37.5 (13.3)</td>
</tr>
<tr>
<td>Average length of illness</td>
<td>2-5 days</td>
<td>3 months</td>
<td>6 months</td>
<td>11.8 years</td>
<td>14.5 years</td>
<td>15.2 years</td>
<td>3.8 years</td>
<td>9.3 years</td>
<td>16.8 years</td>
</tr>
</tbody>
</table>

RESULTS

(1) Reliability and scale intercorrelation

Data collected from the myocardial infarction and renal samples show the IPQ scales to have good levels of both internal consistency and test-retest reliability. These data are represented in Table (2). As would be expected, both the Control Cure and Consequences scales have higher levels of test-retest reliability than the Identity and Time-line scales as patients' perceptions of the consequences and cure of their illness are less likely to change over time.

The intercorrelations between the IPQ scales are shown in Table (3) and demonstrate logical relationships. Patients with a stronger illness identity are more likely to perceive their illness as lasting longer and having more serious consequences. Patients with higher Time-line score are less likely to see their illness as potentially controllable or curable and to have more severe personal consequences.
### Table 2 Internal consistency (Cronbach Alpha) and re-test reliability scores for IPQ scales

<table>
<thead>
<tr>
<th>SCALE</th>
<th>Alpha&lt;sup&gt;1&lt;/sup&gt;</th>
<th>One Month&lt;sup&gt;2&lt;/sup&gt;</th>
<th>Three Month&lt;sup&gt;1&lt;/sup&gt;</th>
<th>Six Month&lt;sup&gt;1&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity</td>
<td>.82</td>
<td>.84**</td>
<td>.34**</td>
<td>.06</td>
</tr>
<tr>
<td>Timeline</td>
<td>.73</td>
<td>.49*</td>
<td>.51**</td>
<td>.36**</td>
</tr>
<tr>
<td>Consequences</td>
<td>.82</td>
<td>.68**</td>
<td>.55*</td>
<td>.55*</td>
</tr>
<tr>
<td>Control/Cure</td>
<td>.73</td>
<td>.68**</td>
<td>.54*</td>
<td>.46*</td>
</tr>
</tbody>
</table>

Note: *p < .01, **p < .001
<sup>1</sup>MI sample
<sup>2</sup>Renal sample

### Table 3 Intercorrelations between IPQ scales in the MI sample (N = 143)

<table>
<thead>
<tr>
<th>SCALES</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity</td>
<td>.20*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Timeline</td>
<td></td>
<td>.52***</td>
<td></td>
</tr>
<tr>
<td>Consequences</td>
<td>.26**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control/Cure</td>
<td>-0.07</td>
<td>-0.32***</td>
<td>-0.09</td>
</tr>
</tbody>
</table>

Note: *P < .05, **P < .01, ***P < .001

### (2) Concurrent Validity

Data from the MI sample at three months post-MI provided the opportunity to test the concurrent validity of the IPQ scales. The correlations between other measures of perceived health and disability as well as recent doctor visits and beliefs about recovery are shown in Table (4). As would be expected, the Identity Scale is positively related to current reported disability, as measured by the Sickness Impact Profile (Bergner, Bobbit, Carter and Gilson, 1981), and recent doctor visits. It is also inversely related to self-rated health and patients' own ratings of control over their heart problems. A higher Time-line score, indicating a belief that illness will last a long time, is positively correlated with patients' ratings of the likelihood of a future heart attack, as well as health distress and with recent visits to the doctor. Time-line scores are negatively correlated with perceived control over heart disease and self-rated health. The Control Cure scale is significantly related to scores on the Recovery Self-Efficacy scale (Partridge and Johnston, 1989) and with patients' perceived control over their heart disease. It is also negatively related to the likelihood of a future MI. Scores on the Consequences scale are positively related to ratings of health distress, disability, the perceived likelihood of a future heart attack and recent doctor visits. Moreover they are significantly negatively related to self-rated health and perceived control over heart disease (see Table 4).

### Table 4 Correlations of IPQ scales with other measures in MI sample (N = 104)

<table>
<thead>
<tr>
<th></th>
<th>Identity</th>
<th>Timeline</th>
<th>Consequences</th>
<th>Control/Cure</th>
</tr>
</thead>
<tbody>
<tr>
<td>SIP total disability score&lt;sup&gt;1&lt;/sup&gt;</td>
<td>.54***</td>
<td>.25*</td>
<td>.34***</td>
<td>-.14</td>
</tr>
<tr>
<td>Recent doctor visits&lt;sup&gt;2&lt;/sup&gt;</td>
<td>.31 **</td>
<td>.17</td>
<td>.21 *</td>
<td>.05</td>
</tr>
<tr>
<td>Health Distress&lt;sup&gt;3&lt;/sup&gt;</td>
<td>.32**</td>
<td>.23*</td>
<td>.53***</td>
<td>-.03</td>
</tr>
<tr>
<td>Recovery Self Efficacy&lt;sup&gt;4&lt;/sup&gt;</td>
<td>.01</td>
<td>-.18*</td>
<td>-.14</td>
<td>.38***</td>
</tr>
<tr>
<td>Self-rated health&lt;sup&gt;5&lt;/sup&gt;</td>
<td>-.55***</td>
<td>-.29**</td>
<td>-.52**</td>
<td>.15</td>
</tr>
<tr>
<td>Likelihood of future MI&lt;sup&gt;6&lt;/sup&gt;</td>
<td>.24*</td>
<td>.42***</td>
<td>.36***</td>
<td>-.28**</td>
</tr>
<tr>
<td>Control over heart problems&lt;sup&gt;7&lt;/sup&gt;</td>
<td>-.30**</td>
<td>-.38***</td>
<td>-.39***</td>
<td>.42***</td>
</tr>
</tbody>
</table>

Note: *P < .03, **P < .01, ***P < .001
<sup>1</sup> Sickness Impact Profile (Bergner, Bobbitt. Carter and Gilson, 1981)
<sup>2</sup> Last 3 months apart from scheduled check-up
<sup>3</sup> Health Distress Scale
<sup>4</sup> Recovery Locus of Control Scale (Partridge and Johnston, 1989)
<sup>5</sup> Rated on a 7 point scale from terrible to excellent
<sup>6</sup> In next 12 months, rated on a 7 point scale from very low to very high
<sup>7</sup> Rated on a 7 point scale from absolutely no control to extreme amount of control
We have also obtained data from patients with severe asthma, comparing their Control Cure scores on the IPQ with scores on an asthma specific version of the Multidimensional Health Locus of Control Scale (MHLC, Wallston, Wallston and DeVellis, 1978). This showed a significant positive correlation with the MHLC `Internal' scale (r = 0.44; p < 0.001), a significant negative correlation with the MHLC `chance' scale (r = -0.37; p < 0.001) and no correlation with the 'Powerful Others' scale. Thus the pattern of these correlations provides further support for the concurrent validity of the Control Cure scale.

(3) Discriminant Validity

To assess the extent to which the IPQ could discriminate between different illnesses we compared the IPQ scale scores in patients with insulin dependent diabetes, rheumatoid arthritis (RA), chronic fatigue syndrome (CFS) and chronic idiopathic pain. Each of these illnesses has distinct presentations and effects on patients' lives. Other common features of these illnesses make them particularly relevant to the concept of illness representations. The precipitating factors and aetiology of all four chronic illnesses are unclear and most treatments emphasise management of symptoms rather than cure. Here, patients' beliefs are likely to have an important impact on their adjustment to their illness. We were specifically interested to see whether, despite uncertain medical explanations for the illnesses, the IPQ scale could help identify distinct patient illness beliefs.

Due to differences in sample sizes, tests for homogeneity of variance were conducted on the length of illness and the age of the subjects. The groups were homogenous for age (Cochran's C = .30, p = .42), but not length of illness (Cochran's C = .41, p < 01). As would be expected, length of illness was significantly correlated with the IPQ Timeline Scale (r = .29, p < .01) but not with any of the other IPQ Scales.

A series of one-way analyses of variance, followed by post-hoc Scheffe tests were conducted on the IPQ scales to assess group differences in illness cognitions. The results of these analyses are presented in the figure and in Tables (5) and (6). Comparing the CFS and pain groups on the IPQ scales, CFS patients had a significantly stronger illness identity, belief in serious consequences and chronic time-line. CFS patients' illness identity and serious consequences beliefs were also significantly higher than those of diabetic patients. RA patients' illness beliefs were distinguished from those with chronic pain by a strong illness identity and chronic time-line, which is consistent with an illness that is characterised by severe joint pain and swelling for which there is no cure. RA patients also had significantly higher identity scores than diabetic patients.

Table 5  IPQ scale mean scores (SD) in diabetes, rheumatoid arthritis, CFS and pain patients

<table>
<thead>
<tr>
<th>COMPONENT</th>
<th>Diabetes</th>
<th>Rheumatoid</th>
<th>CFS</th>
<th>Pain</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness identity</td>
<td>6.56(3.11)</td>
<td>9.05(1.84)</td>
<td>10.42(2.00)</td>
<td>7.02(2.9)</td>
<td>37.53***</td>
</tr>
<tr>
<td>Consequences</td>
<td>3.15(1.00)</td>
<td>3.62(0.97)</td>
<td>4.10(0.75)</td>
<td>3.57(0.89)</td>
<td>13.34***</td>
</tr>
<tr>
<td>Timeline</td>
<td>4.24(0.66)</td>
<td>3.95(0.71)</td>
<td>3.70(0.71)</td>
<td>3.29(1.81)</td>
<td>18.84***</td>
</tr>
<tr>
<td>Control/Cure</td>
<td>3.55(1.51)</td>
<td>3.41(0.04)</td>
<td>3.38(0.59)</td>
<td>3.56(0.58)</td>
<td>1.79</td>
</tr>
</tbody>
</table>

Note: a,b,c,d denotes pairs of groups different at 0.05 level Scheffe test
*P < .05, **P < .01, ***P < .001

Table 6  Illness attribution mean scores (SD) in diabetes, rheumatoid arthritis, CFS and pain patients

<table>
<thead>
<tr>
<th>ATTRIBUTION</th>
<th>Diabetes</th>
<th>Rheumatoid</th>
<th>CFS</th>
<th>Pain</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Germ or virus</td>
<td>2.45(1.03)</td>
<td>2.48(1.08)</td>
<td>3.85(0.84)</td>
<td>1.70(0.6)</td>
<td>76.97***</td>
</tr>
<tr>
<td>Diet</td>
<td>2.35(1.33)</td>
<td>2.24(0.94)</td>
<td>2.24(0.96)</td>
<td>1.82(0.68)</td>
<td>3.61**</td>
</tr>
<tr>
<td>Pollution</td>
<td>1.79(0.78)</td>
<td>2.05(0.92)</td>
<td>3.03(0.99)</td>
<td>1.70(0.5)</td>
<td>44.68***</td>
</tr>
<tr>
<td>Genetics</td>
<td>2.77(1.13)</td>
<td>2.57(1.21)</td>
<td>2.19(0.95)</td>
<td>2.30(0.75)</td>
<td>9.19***</td>
</tr>
<tr>
<td>Chance</td>
<td>2.91(1.30)</td>
<td>3.00(1.05)</td>
<td>2.84(1.24)</td>
<td>2.44(1.21)</td>
<td>2.01</td>
</tr>
<tr>
<td>Stress</td>
<td>2.88(1.24)</td>
<td>2.91(1.06)</td>
<td>2.83(1.2)</td>
<td>2.30(1.03)</td>
<td>3.41*</td>
</tr>
<tr>
<td>My own behaviour</td>
<td>2.12(1.11)</td>
<td>2.09(0.87)</td>
<td>1.67(0.90)</td>
<td>2.88(1.24)</td>
<td>14.90***</td>
</tr>
<tr>
<td>Other peoples</td>
<td>2.01(1.11)</td>
<td>2.09(1.02)</td>
<td>2.42(0.99)</td>
<td>1.97(1.34)</td>
<td>2.17</td>
</tr>
</tbody>
</table>

Note: a,b,c,d,e denotes pairs of groups different at .05 level Scheffe test
*P < .05, **P < .01, ***P < .001
The IPQ Cause scale showed CFS patients to endorse most strongly “a virus” or “pollution” as causes for their illness, with “my own behaviour” being the least favoured attribution. These findings are consistent with other studies that have shown that most CFS patients make external physical attributions for their illness, rather than internal ones (Powell, Dolan, Wessely, 1990; Ray Weir, Cullen and Phillips, 1992). In contrast, pain patients made significantly fewer attributions to viruses and pollution than CFS patients, and were most likely to attribute their condition to their behaviour. This reflects the fact that most pain conditions are triggered by an accident or injury. Pain patients also made significantly fewer stress attributions when compared to diabetic patients, which is consistent with chronic pain patients’ reluctance to adopt psychological explanations for their condition. Diabetic patients selected a genetic cause for their illness significantly more than CFS and pain patients. The RA group were less likely than chronic pain patients to attribute their illness to their own behaviour and more likely to make viral attributions.

These results show that IPQ scale scores distinguished clearly between chronic pain patients and RA patients illness beliefs, even though the central symptom of both these disorders is extreme pain. CFS was also clearly differentiated from the other three illness groups, by having the most negative illness beliefs and distinct attributions.

PREDICTIVE VALIDITY

The predictive validity of the IPQ scales was examined by looking at the correlations between the IPQ scale scores of the MI sample in hospital with a subsequent follow-up assessment at three and six months. These correlations are presented in Table (7) and show the Identity scale to be significantly negatively related with self-rated health at three months follow-up but not at six months. Time-line beliefs at baseline were significantly related to both three and six month ratings of the likelihood of a further MI and the baseline Control Cure scores were significantly related to patients’ three and six month ratings of control over their heart problem and were negatively related to perceived likelihood of future MI at both time points. The baseline Consequences scale score was significantly negatively related to self-rated health at three months and positively related to perceived likelihood of future MI at six months.
Table 7 Predictive validity of IPQ scales: Correlations of baseline IPQ scale scores with measures at the three and six month follow-up in the MI sample

<table>
<thead>
<tr>
<th></th>
<th>Identity</th>
<th>Timeline</th>
<th>Consequences</th>
<th>Control/Cure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Three months follow-up (N = 104)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-rated health</td>
<td>-.24*</td>
<td>-.05</td>
<td>-.28*</td>
<td>-.06</td>
</tr>
<tr>
<td>Doctor visits in past 3 months</td>
<td>.14</td>
<td>.15</td>
<td>.21*</td>
<td>-.07</td>
</tr>
<tr>
<td>Likelihood of future MI</td>
<td>.06</td>
<td>.30*</td>
<td>.19</td>
<td>-.27**</td>
</tr>
<tr>
<td>Control over heart problems</td>
<td>.10</td>
<td>-.02</td>
<td>.16</td>
<td>.35***</td>
</tr>
<tr>
<td>Six months follow-up (N = 115)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-rated health</td>
<td>-.07</td>
<td>-.12</td>
<td>-.18</td>
<td>.10</td>
</tr>
<tr>
<td>Doctor visits in past 3 months</td>
<td>.00</td>
<td>-.10</td>
<td>-.11</td>
<td>-.08</td>
</tr>
<tr>
<td>Likelihood of future MI</td>
<td>.02</td>
<td>.26**</td>
<td>.23*</td>
<td>.20*</td>
</tr>
<tr>
<td>Control over heart problems</td>
<td>-.11</td>
<td>-.07</td>
<td>-.17</td>
<td>.25**</td>
</tr>
</tbody>
</table>

Note: *P < .05, **P < .01, ***P < .001

In another paper we have also examined the relation between baseline illness perceptions in MI patients and subsequent attendance for cardiac rehabilitation and return to work (Petrie, Weinman, Sharpe and Buckley, submitted). These results show that rehabilitation attendance was significantly related to a stronger belief during hospitalisation that the illness could be cured or controlled. Return to work within six weeks was significantly related to lower initial scores on the time-line and consequences subscales. Additional data is needed to assess a wider range of predictive validity in other illness groups, not only with subsequent questionnaire scores but also with important behavioural and social outcomes, such as the resumption of work and other activities, at longer intervals following the onset of illness.

SIGNIFICANT OTHER IPQ VERSION

A significant other version has been tested on a group of 50 MI patients and their spouses. Significant intercorrelations between the IPQ scales administered to MI patients and those administered to their spouses were found for the Consequences scale (r = .27, p < .05), the Control Cure scale (r = .30, P < .05) and Time-line (r = .31, p < .05). The Identity scale which asks the spouse to identify the symptoms that are part of their partner's illness did not reach significance. Inevitably there is considerable variance in the level of agreement between patients' and significant others' illness representations and we feel that this could provide useful insights into the role of careers and others in the recovery process.

DISCUSSION

In this paper we have outlined the development and evaluation of a new questionnaire for assessing patients' representations of illness. The questionnaire was specifically constructed to assess the five components of illness representation described in Leventhal's self-regulation model (Leventhal et al. 1984). Since further work is needed to establish the psychometric status of the IPQ, particularly to provide normative data and internal consistency indices for different populations, the present conclusions should be treated with caution. The data obtained so far indicate that the internal consistency and test-retest reliability of the separate scales are encouraging. The subscales vary in the number of items and the scoring system was developed to produce comparable score ranges. However, the two scales with less items have lower internal consistency and an increase in the number of time line and cure/control items might be worthwhile. However, with the time line items, there are a limited number of ways to express these and they could become rather repetitive for patients if another 3 or 4 items are added.

The one month test-retest reliability coefficients in the renal sample are generally high, as would be expected in a group of patients with a relatively stable, chronic condition. In contrast, the three and six month test-retest correlation coefficients were progressively lower and this is not surprising since self regulation theory proposes that illness representations may change over time. This is especially likely if the illness is unstable or if the “profile” of the illness changes. These test-retest results were obtained from a group of patients who had experienced a first myocardial infarction and it is reasonable to anticipate that their representations may change, especially during the six month period after their heart attack. In particular one might expect to see changes in the identity and time-line components as the patient's illness experience changes For example, the initial heart attack might generate an acute time-line with a clear identity derived from the experience of symptoms such as pain, nausea and breathlessness. As the patient recovers from this acute MI, the illness experience is more likely to be that of a chronic condition which may be asymptomatic or with intermittent
symptomatology (e.g., chest pain on exertion). Thus these changes in MI patients' representations may explain the lower retest correlations on the identity and time line subscales obtained at the three and six month assessment.

The data on the concurrent, discriminative and predictive validity of the IPQ are also encouraging. Expected correlations were obtained between IPQ scales and established measures of disability, coping, self-rated health status and health distress. Self regulation theory predicts that illness representations would be directly associated with coping and, via this, with other outcomes such as mood and disability. In this model coping is a mediating factor between illness representations and outcome. We have certainly found associations IPQ scale scores and coping in patients with CFS (Moss-Morris et al., in press) and in patients with a recent MI. However, in the study of CFS patients we found that IPQ scale scores were more strongly predictive of levels of distress and disability than were coping scores. This indicates that illness representations may well have direct effects on mood and adjustment which are not mediated by coping. Similar findings have been obtained in recent studies of illness representations in chronic illnesses (Earll, 1994) and careers of stroke patients (Martin, 1994).

Much of the early data on illness representations was obtained during interviews in which patients were invited to speak openly about their illness (Leventhal and Nerenz, 1985). Open or semi-structured interviews provide qualitative information which may facilitate a deeper understanding of the individual's representations and experience of illness. However, such data is time consuming and expensive to collect and analyse which severely limits the sample size of most qualitative studies. In contrast, a questionnaire method for eliciting illness representations facilitates investigation of illness perceptions in larger samples. Additional support for concurrent validation of the IPQ was obtained from a study, mentioned earlier, in which 52 diabetic patients received a structured interview as well the IPQ. Half the patients were interviewed prior to the IPQ and the other half were asked to complete the IPQ immediately before being interviewed. There was a close fit between interview and questionnaire data and no order effects were found for the content of IPQ responses; the pattern of IPQ responses did not differ between those received the questionnaire followed by interview and those who were interviewed prior to receiving the questionnaire. However, patients found the IPQ easier to complete when they had been interviewed first, even though the data from the latter was not always complete. We believe that this might be due to a “priming effect” since the interview may have served to activate the appropriate illness schemata, hence facilitating the subsequent completion of the questionnaire. This finding is similar to that of Bishop and colleagues who have demonstrated how illness prototypes can be primed, thereby speeding up subsequent response times on a related task (Bishop, 1991). In practical terms, this suggests that if there is sufficient time, then the administration of the IPQ may be preceded by a brief interview focusing on the patient's ideas about the nature, cause, time line, controllability and consequences of their illness.

Users may wish to amend the IPQ to include items which are specific to particular illness or patient groups. For example, in one of our studies of patients with CFS, we included thirteen additional symptom items in the identity scale, as well as including additional “consequences” and “cause” items which were particularly relevant to this group (Moss Morris et al. in press). Similarly we have devised equivalent versions with slightly modified wording to assess spouse's or career’s perceptions of the patient's illness (e.g. Martin, 1994).

In conclusion, we believe that the IPQ could have considerable scope in health psychology research. There is growing interest in patients' representations of their illness for understanding the psychological impact of illness (e.g. Skelton and Croyle, 1991), for explaining patterns of care seeking and adherence to treatment advice (Cameron, Leventhal and Leventhal 1993; Leventhal and Cameron, 1987) and examining the responses to psychological interventions, particularly those with a cognitive-behavioural focus (Pimm, Byron, Curson and Weinman, 1994). The IPQ is a simple, flexible method for assessing illness representations and we hope that it will prove to be of value in facilitating further research into illness perceptions.

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APPENDIX (1)

Illness Identity (Core symptom list)

(please indicate how frequently you now experience the following symptoms as part of your (illness))

Rated: all of the time, frequently, occasionally, never

Pain
Nausea
Breathlessness
Weight Loss
Fatigue
Stiff Joints
Sore Eyes
Headaches
Upset Stomach
Sleep Difficulties
Dizziness
Loss of Strength

We are interested in your own personal views of how you now see your (illness).
Please indicate how much you agree or disagree with the following statements about your illness.

Rated: Strongly agree, agree, neither agree nor disagree, disagree, strongly disagree

Cause
A germ or virus caused my illness
Diet played a major role in causing my illness
Pollution of the environment caused my illness
My illness is hereditary - it runs in my family
It was just by chance that I became ill
Stress was a major factor in causing my illness
My illness is largely due to my own behaviour
Other people played a large role in causing my illness
My illness was caused by poor medical care in the past*
My state of mind played a major part in causing my illness*

*(N.B. The last two cause items have been added since some the earlier studies and hence do not appear in Table 6).

Time-line
My illness will last a short time
My illness is likely to be permanent rather than temporary
My illness will last for a long time

Consequences
My illness is a serious condition
My illness has had a major consequences on my life.
My illness has become easier to live with
My illness has not had much effect on my life.
My illness has strongly affected the way others see me
My illness has serious economic and financial consequences
My illness has strongly affected the way I see myself as a person

Control/Cure
My illness will improve in time
There is a lot which I can do to control my symptoms
There is very little that can be done to improve my illness
My treatment will be effective in curing my illness
Recovery from my illness is largely dependent on chance or fate
What I do can determine whether my illness gets better or worse

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References


Petrie, K., Weinman, J., Sharpe, N. and Buckley, J. Predicting return to work and function following myocardial infarction: The role of the patient's view of their illness Paper Submitted for publication.


