PATIENTS’ ILLNESS PERCEPTIONS
Do they matter and can we change them

Rona Moss-Morris
Professor of Psychology as Applied to Medicine
Common Sense Model of Illness Representations

Developing and testing theory based psychological interventions for long term conditions
Key themes:

Why they important

Measurement

Techniques to alter illness representations and related coping

Do these techniques work?

Revising the common sense model
COMMON SENSE MODEL OF ILLNESS REPRESENTATIONS (Leventhal et al., 1984)
Stimuli: symptoms or illness

Cognitive representation of illness

Coping with objective features of illness

Evaluation of coping

Stimuli: symptoms or illness

Emotional reaction to illness

Coping with emotional reaction

Evaluation of change in emotional reaction

The IPQ crew


Moss-Morris, R. et. al. (2002) Illness Perception Questionnaire Revised (IPQ-R). *Psychology and Health*
Illness Perception Questionnaire Revised (IPQ-R)

- Identity
- Timeline
- Consequences
- Causes
- Control/cure

Personal control
Treatment Control
Illness Coherence
Emotional representations
Illness Representations and Coping in Functional Syndromes
Functional Somatic Syndromes

- Characterised more by symptoms, suffering, and disability than by disease specific, demonstrable physiological abnormalities

- Different syndromes tend to be clinically defined by one or more prominent symptoms
  - Irritable bowel syndrome (IBS)
  - Chronic fatigue syndrome (CFS)
  - Fibromyalgia
Common Sense model in Chronic Fatigue Syndrome

233 CFS patients

IPQ explained between 30% – 47% of the variance in disability, psychological well-being and fatigue

Coping strategies (COPE, Carver et al., 1989) accounted for little of the variance in adjustment

Coping (Folkman & Lazerus, 1984)

Problem-focused coping:

attempts to modify, reduce, or eliminate the source of stress

Emotion-focused coping:

attempts to alter the emotional response to the stressor
Coping behaviours versus coping strategies.

COPE Problem focused: Active Coping

• I've been taking action to try to make the situation better.

Common sense model

• coping behaviours e.g. go to the GP.
Limiting

I have put my life on hold

All-or-nothing

I find my self rushing to get everything done before I crash
Precipitants of Functional Syndromes

Chronic Fatigue Syndrome (CFS)
  • Infectious mononucleosis (glandular fever)

Irritable Bowel Syndrome:
  • Campylobacter (food poisoning)

Post Concussion Syndrome
  • Mild traumatic brain injury
Predictors of onset of IBS, CFS and PCS at 3 and 6 months

Higher levels of:

- Anxiety and depression

- Perfectionism

- Negative acute illness/injury beliefs
  - Symptoms long lasting
  - uncontrollable
  - distressing
  - serious consequences

- All-or-nothing behaviour

# Univariate Predictors of PCS

<table>
<thead>
<tr>
<th>Variable</th>
<th>PCS at 3 months</th>
<th></th>
<th></th>
<th>PCS at 6 months</th>
<th></th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>OR (95% CI)</td>
<td>p Value</td>
<td>OR (95% CI)</td>
<td>p Value</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BIPQ</td>
<td>1.047 (1.016 to 1.079)</td>
<td>0.003**</td>
<td>1.066 (1.030 to 1.104)</td>
<td>0.000**</td>
<td></td>
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</tr>
<tr>
<td>IES</td>
<td>1.026 (0.999 to 1.053)</td>
<td>0.057</td>
<td>1.048 (1.019 to 1.078)</td>
<td>0.001**</td>
<td></td>
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</tr>
<tr>
<td>HADS anxiety</td>
<td>1.116 (1.011 to 1.231)</td>
<td>0.029*</td>
<td>1.175 (1.058 to 1.304)</td>
<td>0.003**</td>
<td></td>
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</tr>
<tr>
<td>HADS depression</td>
<td>1.079 (0.969 to 1.201)</td>
<td>0.166</td>
<td>1.136 (1.018 to 1.268)</td>
<td>0.022*</td>
<td></td>
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</tr>
<tr>
<td>BRIQ all-or-nothing</td>
<td>1.141 (1.050 to 1.240)</td>
<td>0.002**</td>
<td>1.190 (1.087 to 1.304)</td>
<td>0.000**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BRIQ limiting</td>
<td>1.044 (0.981 to 1.111)</td>
<td>0.174</td>
<td>1.041 (0.977 to 1.109)</td>
<td>0.217</td>
<td></td>
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</tr>
<tr>
<td>Litigation/compensation</td>
<td>1.718 (0.573 to 5.153)</td>
<td>0.334</td>
<td>2.722 (0.919 to 8.066)</td>
<td>0.071</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSQ availability</td>
<td>0.943 (0.757 to 1.176)</td>
<td>0.604</td>
<td>0.960 (0.761 to 1.210)</td>
<td>0.728</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSQ satisfaction</td>
<td>0.784 (0.509 to 1.209)</td>
<td>0.272</td>
<td>0.764 (0.484 to 1.206)</td>
<td>0.247</td>
<td></td>
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</tr>
</tbody>
</table>

*p ≤ 0.05, **p ≤ 0.01.

BIPQ, Brief Illness Perception Questionnaire; BRIQ, Behavioural Response to Illness Questionnaire; HADS, Hospital Anxiety and Depression Scale; IES, Impact of Event Scale; PCS, postconcussional syndrome; SSQ, Social Support Questionnaire.
Multivariate Analyses of PCS

3 months
Overall model predicted 76.4% of cases

6 months
Overall model predicted 82.9% of cases
Stimuli: symptoms or illness

Cognitive representation of illness

Coping with objective features of illness

Evaluation of coping

Emotional reaction to illness

Coping with emotional reaction

Evaluation of change in emotional reaction

Does Coping mediate between illness representations and outcome?

Injury Perceptions → All-or-nothing behaviours

All-or-nothing behaviours → PCS symptoms (6 months)

Total effect = .248, p < .01; indirect effect = .085, p = .06
I TOLD YOU I WAS SICK

B. P. ROBERTS

MAY 17, 1929

JUNE 18, 1979
MEASUREMENT ISSUES: Beyond the standard IPQ
IPQ Measurement issues

IPQ was developed as a generic instrument

IPQ-R instructions specify the need to pilot and tailor the instruments for specific illness groups

Treatment control subscale fails to take into account multiple treatments

Increase in multi-morbidity - IPQ measures beliefs about one illness
The Use of Reliever Medication in Asthma: The Role of Negative Mood and Symptom Reports

Key Asthma Symptoms

- Tight Chest
- Cough
- Wheeze
Illness identity – the symmetry rule

- **Illness label**
- **Symptom or bodily sensations**
## Adapted illness identity scale

<table>
<thead>
<tr>
<th>Do you experience these symptoms</th>
<th>Related to your asthma</th>
<th>Related to side effects of medication</th>
<th>Related to stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tight chest</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cough</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wheeziness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of strength</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Symptoms patients associated with asthma

- Upset Stomach
- Nausea
- Sore Throat
- Body Tension
- Pounding Heart
- Shakiness
- Headache
- Flushed Face
- Loss strength
- Fatigue
- Tight Chest
- Breathless
- Wheezy

Percentage of subjects attributing symptom to asthma
Understanding the Relationships

Attributing non-asthma symptoms to asthma

Distress

Lung function

Reliever Use
Adapting the IPQ-R for different illness groups

Qualitative interviews to explore beliefs
• inductive thematic analysis
• deductive analysis related to IPQ dimensions

Draft of adapted or new questionnaire
• revise based on think allowed interviews

Quantitative psychometric analysis
Research report

Are patient beliefs important in determining adherence to treatment and outcome for depression? Development of the beliefs about depression questionnaire

Jeannette Lynch\textsuperscript{a,}\textsuperscript{*}, Michael Moore\textsuperscript{b}, Rona Moss-Morris\textsuperscript{c}, Tony Kendrick\textsuperscript{d}

\textsuperscript{a} Primary Medical Care Group, University of Southampton, United Kingdom
\textsuperscript{b} Primary Care Research Network, Primary Medical Care Group, University of Southampton, United Kingdom
\textsuperscript{c} School of Psychology, University of Southampton, United Kingdom
\textsuperscript{d} Hull York Medical School, United Kingdom
Beliefs about Depression Scale

**Personal control**
- control through thoughts and behaviours
- control through keeping busy and exercise

**Treatment Control:**
- talking therapy
- alternative therapy
- anti-depressant medication

**Primary care patients with recent diagnosis of depression (n=292)**
- keeping busy/exercise
- talking therapies

predicted reductions in distress 6 months later
‘The chicken and egg thing’: Cognitive representations and self-management of multimorbidity in people with diabetes and depression

Jennifer Mc Sharry\textsuperscript{a*}, Felicity L. Bishop\textsuperscript{b}, Rona Moss-Morris\textsuperscript{c} and Tony Kendrick\textsuperscript{d}
Diabetes and Depression Representation and Management Questionnaire (DDRMQ)

Separate Representations

Linked Representations

Diabetes and Depression Management

Separate Management

Linked Management

Multi-Medication Issues

non-adherence

Higher distress
Poorer blood glucose control

(Mc Sharry et al in press JAD)
How do we change illness representations and related coping behaviour?

Intervention Components
Illness Coherence: Presenting the shared model of symptoms: Example of IBS

The goal is provide a coherent understanding of symptoms in a way that engages patients in CBT.

Validate the symptoms using a physiological model.

Move towards the role of psychosocial factors as maintaining factors.
Dysregulation of the movements and sensitivity of the colon

**Segmentation**
Segmentation describes a series of ring-like contractions that occur at regular intervals; these churn and mix faeces but do not propel them.

**Peristaltic contractions**
Waves of peristaltic contractions propel faeces toward the rectum. Muscles behind food contract, while the muscles in front relax.

**Mass movements**
Mass movements are strong peristaltic waves that propel faeces relatively long distances about two or three times a day.
Link enteric nervous system to Autonomic nervous system
TRIGGER
(Infection, stress or both)

Changes in bowel function

Bowel symptoms

Disrupts daily routine and/or eating habits

More bowel symptoms and worry about health

Disruption of social/work life

Stress/anxiety
Changing all-or-nothing or avoidance behaviour

Education

Self monitoring diary to assess daily activity, sleeping and eating patterns

Jointly agree behaviours to change

Goal setting.

• Realistic - break down into component parts
• Specific - what, where, when
• Self-monitoring and review of goals
Managing Your MS Fatigue
A Practical Approach
# Changing illness identity – MS relapse

<table>
<thead>
<tr>
<th>My symptoms of MS</th>
<th>Related to relapse</th>
<th>Related to side effects of medication</th>
<th>Related to stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td></td>
<td>yes</td>
<td>maybe</td>
</tr>
<tr>
<td>Headache</td>
<td></td>
<td>yes</td>
<td>maybe</td>
</tr>
<tr>
<td>Pins &amp; needles</td>
<td>yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of strength</td>
<td>yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of vision</td>
<td>yes</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Changing negative representations of symptoms

<table>
<thead>
<tr>
<th>Situation</th>
<th>Feeling</th>
<th>Unhelpful thought</th>
<th>Alternative thought</th>
</tr>
</thead>
<tbody>
<tr>
<td>About to go out for dinner with a friend.</td>
<td>Anxious</td>
<td>There is no way I can go out with this fatigue. I will never enjoy myself.</td>
<td>If I don’t focus on the fatigue it may not seem so bad and I might enjoy myself more.</td>
</tr>
</tbody>
</table>
Techniques embedded within use of clinical skills

**Basic therapeutic communication**
- Open questions
- Empathy
- Reflection

**Guided discovery – Socratic questions**

**Developing agreed goals.**

**Motivational interviewing**

**Values based action**
Context of techniques: Adding the how to the what.

- Self-help versus guided self help versus therapy
- Use of basic communication/therapy skills
- How many sessions to deliver technique?
- Homework or practice tasks?
- Expertise of the HCP
Do these techniques work?
A randomized controlled trial of a cognitive behavioural therapy-based self-management intervention for irritable bowel syndrome in primary care

R. Moss-Morris\textsuperscript{1*}, L. McAlpine\textsuperscript{2}, L. P. Didsbury\textsuperscript{2} and M. J. Spence\textsuperscript{3}

\textsuperscript{1} School of Psychology, University of Southampton, UK
\textsuperscript{2} ProCare Psychological Services, Auckland, New Zealand
\textsuperscript{3} Department of Psychological Medicine, The University of Auckland, Auckland, New Zealand
Changes in illness-related cognitions rather than distress mediate improvements in irritable bowel syndrome (IBS) symptoms and disability following a brief cognitive behavioural therapy intervention

Joseph Chilcot, Rona Moss-Morris*

*Health Psychology Section, Psychology Department, Institute of Psychiatry, King's College London, UK
How did CBT lead to a reduction in symptoms?

Reduction in
- negative illness beliefs ✓
- symptoms as damage ✓
- biological attributions ✓
- anxiety and depression xx
- all-or-nothing behaviour x

CBT ➔ Improvement in IBS
Change from negative to positive beliefs about IBS
Conclusions

Negative perceptions of IBS key mediator of change in relation to IBS symptoms and related impairment

All-or-nothing behaviours not a mediator
Related to early onset IBS rather than on-going chronicity?

Change in IBS-related avoidance and toileting behaviours have been shown to mediate change. (Reme et al. 2011)
Can CBT reduce fatigue in MS?

Cognitive behaviour therapy compared to relaxation training for multiple sclerosis fatigue: A randomized controlled trial.

Which cognitions and behaviours mediate the positive effect of cognitive behavioural therapy on fatigue in patients with multiple sclerosis?

H. Knoop\(^1\), K. van Kessel\(^2\) and R. Moss-Morris\(^3\)*

\(^1\) Expert Centre for Chronic Fatigue, Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands
\(^2\) Department of Psychology, University of Auckland, Auckland, New Zealand
\(^3\) School of Psychology, University of Southampton, Highfield, Southampton, UK
Total Positive Perceptions of fatigue

![Graph showing changes in Total Positive Perceptions of fatigue over time.](image_url)
Why does CBT work?

Treatment Group

Change in negative perceptions of fatigue

Fatigue
Stimuli: symptoms or illness

Cognitive representation of illness

Coping with objective features of illness

Evaluation of coping

Stimuli: symptoms or illness

Emotional reaction to illness

Coping with emotional reaction

Evaluation of change in emotional reaction

Role of illness representations in long term conditions

- Environment
- Illness representations
- Behaviours to manage illness
- Physiology
- Emotional responses

Outcomes
Adding implicit cognitive processes to the model

Negative Illness Representations → Attentional bias → Interpretive bias

Attentional bias modification
Thank you to my many inspiring collaborators at the Universities of Auckland, Southampton and KCL

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